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PROVIDING A COMPREHENSIVE AND COMPASSIONATE LONG-TERM HEALTH CARE PROGRAM FOR AMERICA'S SENIOR CITIZENS

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

NINETY-NINTH CONGRESS

SECOND SESSION

NEW HAVEN, CT

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PROVIDING A COMPREHENSIVE AND COMPASSIONATE LONG-TERM HEALTH CARE PROGRAM FOR AMERICA'S SENIOR CITIZENS

MONDAY, JULY 7, 1986

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
New Haven, CT.

The special committee met, pursuant to notice, at 10 a.m., in the Bella Vista Community Center, 31 Eastern Street, Hon. Christopher J. Dodd presiding.

Present: Senator Dodd.

Also present: Deborah L. Hardin, legislative assistant; and William Benson, professional staff.

OPENING STATEMENT BY SENATOR CHRISTOPHER J. DODD, PRESIDING

Senator DODD. Good morning, everyone. I am going to call, if I may, this hearing together.

First of all, let me express my deep gratitude to Bella Vista, to the folks who always make this what everyone considers to be one of the finest institutions in the State for our older citizens. I am delighted to once again be back to this particular facility, and to welcome all of you here this morning.

We are all here this morning because we share a very strong and common concern, and that is the long-term health care needs of the growing population of older Americans.

I have called this hearing of the Senate Special Committee on Aging for a very simple purpose, indeed.

I need to get the benefit of your views, your expertise, and your insights so that I can be better equipped to ensure that the long-term health care needs are met, not only in Connecticut but, of course, across this country, and that they be met comprehensively and compassionately now and in the future.

I am sure that most of you have heard a version of the 17th century poem which begins, "Grow old with me. The best is yet to be; the last of life for which the first was made."

Unfortunately, for many of our older Americans who experience chronic disability or illness, the latter years of life are not always full of poetic discovery and dignity.

And I am convinced that our failure to provide a comprehensive and compassionate long-term health care program is largely to blame for that.

Today, 1.5 million older Americans live in nursing homes across this country.

In addition, the number of senior citizens who are living in their homes or the community with some form of chronic illness requiring medical assistance is estimated to be over three times that figure.

And the need for long-term care can only continue to grow.

The number of Americans aged 65 and older will more than double by the year 2030. Even more telling is the fact that the number of senior citizens over 85, those who are most likely to need some form of long-term care, will increase in that same period more than fivefold.

The hearing this morning will focus primarily on one aspect of the long-term health care issue; that is, the availability and quality of existing home and community based, as opposed to institutional, long-term health care services.

I want to emphasize, first, that I am not opposed to nursing home care at all. To the contrary, I happen to believe that, for many of our elderly citizens, nursing homes offer the most appropriate form of long-term care, especially as the severity and medically dependent nature of the chronic illness increases.

But I do not believe that nursing home care should be, as it has been in the past, the bedrock of our developing national long-term care policy.

First, it is simply too expensive, especially for those elders whose chronic illness is not fully debilitating.

Currently, just over half of all nursing home expenses are paid by the patient, at the whopping cost of $15 billion a year.

Medicare simply does not pay for any long-term care services.

While Medicaid does foot about 50 percent of the Nation's annual nursing home bill, it begins to pay only after the patient has spent down his or her assets to meet the program's eligibility requirements.

That, unfortunately, comes all too quickly. Sixty-three percent of elderly individuals without a spouse completely impoverish themselves after only 13 weeks at a nursing home, and 80 percent do so within a year.

But even more importantly, I believe that long-term care rendered in the home or the community, as opposed to the nursing home, where possible, holds the most promise that the lives of our elderly will be full of autonomy, productivity, and dignity.

One of Connecticut's own senior citizens, the renowned literary critic, Malcolm Cowley, wrote a book on the eve of his 80th birthday, entitled "A View From 80," in which he describes what it is like to grow old in today's society.

Mr. Cowley writes about the fear of becoming helpless. And I quote him:

> It is the fear of being as dependent as a young child, while not being loved as a child is loved, but merely being kept alive against one's will.

He then quotes, the poet does, a letter written by an equally young classmate who wrote, and I quote:

> My only fear about death * * * is that it will not come soon enough. * * * Happily, I am not in such a discomfort that I wish for death, I love and am loved, But please God [let me] die before I lose my independence.

Maximum independence should be the goal of any national long-term health care policy. We should keep as independent as possible, for as long as possible, as many of our chronically ill senior citizens as possible.

I believe a policy focused on home- and community-based alternatives to institutional care stands the best chance of accomplishing that goal.

Unfortunately, national studies show that up to 30 percent of our elders now living in nursing homes across the country are there because they looked for but could not find adequate outpatient health care services to allow them to remain independent in their own homes.

Our long-term care program must start by providing the medical and support services which make it possible for the elder person to live in his or her home.

In addition, nearly 75 percent of nursing home residents are without a spouse, as compared to just over 40 percent of noninstitutionalized elderly citizens.

These statistics tend to suggest that the absence of a spouse or family member who can provide informal health support, even where in-home medical and support services may otherwise be available, is the single most critical factor in determining whether an elderly person will be placed in a nursing home at all.

Therefore, any long-term care program must ensure the availability not only of the necessary services, but also of caregivers who can link those services with the chronically ill senior citizen.

In developing and implementing such a national long-term health care policy, aimed at keeping chronically ill elders in their homes or communities wherever possible, the Federal Government, it seems to me, must work in joint partnership with State and local governments and the private sector.

Here in Connecticut, such a partnership is already in place, working to provide a coordinated network of medical and social services for our chronically ill senior citizens.

Among the many members of that partnership are private corporations, such as the Travelers, which has, commendably, taken the lead in examining the special needs of the family caregiver employee.

In addition, religious and other volunteer groups, such as the Connecticut Interfaith Caregivers Network, contribute invaluably to the long-term health care program by providing the necessary health and support services to the appropriate elderly citizens.

The hearing this morning will be a time to celebrate the ways in which the Connecticut long-term care partnership is strong and effective, to serve as an example for the rest of the Nation.

As most of you already know, just last week, Governor O'Neill announced the formation of a State commission which will report early next year on the financing of long-term health care.

I congratulate and commend the Governor for taking this lead, and I look forward with keen and concerned interest to the significant results the commission will, no doubt, yield.

The main purpose of this hearing, however, is to dispassionately locate and critically assess the ways in which our national long-term health care program needs to be strengthened and, selectively, to find the most appropriate ways to achieve that strengthening.

We have got a long way to go before we can even call what our country's got a "national long-term health care policy."

That policy must be developed comprehensively, compassionately, and responsibly, but very quickly, as well, because the health care needs of today's and tomorrow's elderly simply will not wait nor go away.

And I thank you for listening.

I should announce and tell you that I am delighted that we have such a distinguished group of witnesses overall this morning, each of whom has a very special expertise or understanding to contribute on the issue of long-term care of the elderly.

I am also fortunate that we have as our special guests representatives from the public and private sector to give their expertise on and concern for this issue.

And if time remains at the end of the witnesses' testimony, we will open up this hearing to take questions directly from the audience.

For those of the audience who have comments on this issue of long-term care for the elderly, they can fill out these sheets we have distributed and, if there is time, we will try and get to those questions, as well.

Our first witness is a single panel, if you will—Mrs. Dorothy Kelly.

I will invite Mrs. Kelly to come and join us up here, if she will.

Mrs. Kelly is a resident of Hamden, and we have invited her to share with us her personal experience and insights in this area of long-term health care.

We welcome you this morning, Mrs. Kelly, and we invite you to share with us your own comments before we get to the public and private officials to talk about specific things that they are doing.

We thank you for being with us this morning.

STATEMENT OF MRS. DOROTHY KELLY, HAMDEN, CT

Mrs. KELLY. Good morning. My name is Dorothy Kelly. I live in Hamden, CT. I would request that my name be kept private.

I am 72 years of age. My husband is 75. We celebrated our 50th wedding anniversary last week.

My husband has been ill for 38 years. In those years, he has been able to control one side of his brain. Within the last 5 years, has been partially bedridden. For the last 2 years, he has been completely bedridden.

Now, doctors have not really diagnosed his illness. His condition has been chronic, and he has good days and bad days.

When he was hospitalized, they did not want me to take him home. They said he had to go into a convalescent home, and I had quite an argument with them because they said it would be too much for me to take care of him.

I wanted to bring him home because I knew he would be a lot happier in his home, in his own surroundings.

Also, I felt it was cheaper to keep him at home. I did get him at home after arguing with the hospital staff.

In the end, I had to pay for the IV equipment and supplies because Medicare would not pay because he was not hospitalized. My husband had hiccups for 1 month. The IV treatment stopped the hiccups.

Now, my husband needs constant care, and I feel that CCI and respite services have helped me to take care of my husband at home.

Respite care is so important and, in the past, I have had some health care which has relieved me and helped me tremendously.

I do not know if I could continue if it ever stops. I would hope that the Government, in the future, would encourage health care at home and keeping the elderly happy in their homes. Thank you.

Senator **DODD**. Thank you very much, Mrs. Kelly. Can I ask you a couple of questions?

I would just repeat—for those who may not have heard Mrs. Kelly from the media—I am going to ask the press, if they would, to respect her request that her name not be used, respect her privacy.

Certainly, she has been very kind and gracious to come forward and talk about her situation.

I would emphasize that what you will hear and what you have heard from Mrs. Kelly is not unique.

Sometimes witnesses are asked to come forward because they have a unique story to tell.

Her story is not unique. So, when you relate the facts of her particular situation, you will be accurately portraying what happens to thousands of people in this State and across this country.

First of all, just on a personal note, Mrs. Kelly, you have made the choice, obviously, to have your husband at home.

Could you share with us why you think that is particularly important?

Obviously, there are alternatives to that, but you wanted to keep him at home. Why?

Mrs. **KELLY**. Well, for one thing, he made a request; that he wanted to be home, and he did not want to die in a convalescent home. And he was happier in his own surroundings.

This is why I felt that I would take him home, and he was content.

It is very depressing in a convalescent home when you are—as I say, he is ill. But, at times, he would seem pretty good and, at times, he would seem bad.

So, when he is good, he is a lot happier to be in his own home.

Senator **DODD**. Mrs. Kelly just said, for those in the back, that it was a question of choice; that he felt happier being in his own home; that he has days when he actually feels quite good.

And, if he is going to pass on, he would rather pass on in his own surroundings rather than in some nursing home, where he does not know anybody or could not even look out his own window.

Mrs. **KELLY**. He likes to be able to look out his own window.

Senator **Dodd**. It sounds like no big deal maybe to some people, but to be able to look out your own window means a great deal to a lot of people.

What sorts of services could be provided or would make it easier for your husband to be in the home?

You talked about respite care. I wonder if you might mention some of the other services that would make it easier for you to be able to keep your husband at home.

Mrs. **Kelly**. Well, yes. As I say, everyone needs to get away for a couple of hours, even a day, for relaxation.

Senator **Dodd**. You are talking about yourself in this particular situation?

Mrs. **Kelly**. Yes. If you have the home help, they help, but they cannot be there all day. So, naturally, there are days that I have to be alone with him all day.

And I have got to have a couple of hours off. And that is fine. I mean, you want to do for the person, but this respite care would help as far as helping the person who is taking care of someone.

Senator **Dodd**. You look like a pretty strong woman, but there are, I presume, certain functions, just the grooming, the bathing, for instance, that your husband may need; it is important to be able to have someone there, I presume, who can help you with some of those things, also.

Not only to be able to get away with the respite care but, also, even when you are there, how much do you feel you can actually take care of him, physically, when he is particularly in need?

Mrs. **Kelly**. Well, first of all, I have been doing it for quite a while. Not everybody is like me. There are some people that have to have more help than I do.

But, I mean, the nurse I have been having over, the visiting nurse—CCI has been terrific. They have come in and helped.

And, as I said, if I could get away for a couple of days—they are snappy and all but, as I say, he has got his good days and he has got his bad days.

But that is where I feel respite care, if they could come in and help the person, would help. But it is so much cheaper to keep a person home because you work hard—and, if they go into a convalescent home, how much is left?

Senator **Dodd**. Do you mind telling us how much you pay to—or, how you pay for the care of your husband at home?

Mrs. **Kelly**. The nearest CCI I do not have to pay for; that is covered.

But Medicare stops after so long with the visiting nurse. But, as I say, CCI has picked it up and helped me on that, but that cannot continue. They have to have funds, too.

Senator **Dodd**. But do you find that, aside from the CCI and some of the things you suggested, in terms of the normal shopping and other things you do—I mean, you are able to pay for that out of whatever Social Security or other retirement benefits you have.

Is that relatively adequate enough to take care of the basic needs, aside from the things you talked about?

Mrs. **Kelly**. Well, that's what I said. They have come in to go shopping and things like that; they have done that.

But, as I said, that is going to cut out, naturally, because they have not got the funds to continue with it.

And, see, sometimes, an aide will come in from 8 to 9 or 8 to 10. Well, meanwhile, you cannot do an awful lot in that time.

But you cannot expect them always; there are other people sick besides my husband; I realize that. And I am grateful for what I can get, you know, as help.

But, as I say, I do not know how I will ever continue if it does not continue on.

Senator DODD. What would it do to your economic situation if you had to place your husband in a nursing home?

Mrs. KELLY. I would never do it. I am sorry, but I am going to keep him home. He has been a good man, and we are happy.

And I just would not do it, no matter how hard it got to be.

I think every elderly person wants to stay at home. They do not want to go to a convalescent home. I know I will keep him home. I only have enough money saved to pay for 1 month in a nursing home.

Senator DODD. Well, he is a pretty lucky guy, Mrs. Kelly, and you are wonderful to come by here this morning.

I thought it important at least to hear one person's story of what was going on. And we will do whatever we can to get you help, but you have got an awful lot of people in the State who care deeply about you and the other Mrs. Kellys, if you will, around the State.

So, we thank you. Please, sit and listen to the rest of the testimony here this morning.

Mrs. KELLY. Thank you.

Senator DODD. Thank you very much.

I should mention that we have some distinguished guests in the audience who may have some comments.

Steve Heintz, who is sitting up front, who is our commissioner on income maintenance in this State—we are delighted to have Stephen here this morning as well.

And maybe if we get to an appropriate point in the testimony, you may have some thoughts or comments, as well. I appreciate your coming down.

I am now going to ask our next panel of witnesses to come and sit up here. It is a little crowded, but we are going to try to make do.

The panel consists of Mary Ellen Klinck, the commissioner of our State department on aging—actually, we could have all come down in a car together. Where I live, Mary Ellen lives on one side of me and Steve Heintz lives on the other side of me. So, it is known as Murderers' Row in East Haddam, I guess.

They all want to know why we cannot get the bridge fixed with all the political clout we have.

Mary Ellen has been the commissioner for over 3 years and has provided leadership in all areas for the elderly. She has developed strong support all across the State for her efforts.

Dr. Adrian Ostfeld is here as well. He is a professor of epidemiology and public health at the Yale University School of Medicine, and was a consultant to the White House Council on Aging in 1981.

A recent Hartford Courant article, I might add, described Dr. Ostfeld's knowledge on health issues on aging as encyclopedic. We are delighted to have the doctor here with us, as well.

Audrey M. Wasik, who is also a good friend, is here. Audrey was appointed by the Governor to be the coordinator of the State commission on long-term care. She has an unequaled knowledge of this area, and we are delighted to have her with us this morning.

Ms. Elizabeth Daubert is with us, executive director of the Connecticut Association for Home Care, Inc., a statewide association, and she will be able to give us a practitioner's point of view.

Lastly, we have Ms. Joan Quinn, president of Connecticut Community Care, Inc., which administers the department of aging's promotion of independent living program and, beginning this month, the department of income maintenance's community-based waiver project.

We look forward to hearing your testimony, as well.

I would ask that you all testify in the order in which I have introduced you, and try, if you can, to keep the remarks down to several minutes. If there are prepared statements, they will be made a part of the permanent record of this hearing and available for all to read in detail.

So, if there are prepared statements, consider them accepted, as read.

If you want to paraphrase them or read them directly, whatever you think is best, perhaps we could keep it down to about 5 or 7 minutes apiece, and get to the questions.

I want to mention, by the way—and I should have at the outset—I invited Ben DiLieto, the mayor of New Haven, to be with us this morning, the distinguished mayor and good friend, whom I think almost has an office here at Bella Vista, he spends so much time up here.

He is not going to be able to get by this morning, but people from his staff will be here.

We also are going to be seeing to it that he gets the information resulting from this hearing, as well.

Mary Ellen, again, we are delighted to have you with us this morning.

STATEMENT OF MARY ELLEN KLINCK, COMMISSIONER, CONNECTICUT DEPARTMENT ON AGING

Commissioner **Klinck**. Good morning, Senator Dodd and distinguished members of the panel and my many friends and friends of the elderly out here in the audience.

First, let me tell you what a pleasure it is to be here and to be asked by Senator Dodd to speak at this very, very important hearing today.

The health needs of our elderly is certainly something that we are all concerned about.

During my 3½ years as Connecticut's State Commissioner on Aging, I have had the privilege of representing this special constituency.

What we have today in our great State we owe to their efforts. Our older citizens have built our cities, farmed our fields, educated our young, and cared for our sick.

I am very, very pleased to represent those people.

A great deal is written about the jobs that become obsolete because of new technology or changing markets. This will never be the case for those of us in elderly services.

I am going to give you a few statistics. Between 1970 and 1980, Connecticut's overage-60 population, which currently numbers 600,000, is growing at a rate 10 times faster than the overall population.

Nationally, the older population increased twice as fast as the rest of the population.

An analysis of this population explosion is even more startling because the most rapid population growth is among those over the age of 85.

Between now and the year 2000, our 85-and-over population will more than double, increasing from 35,000 to 75,000.

As a result, the impact on health and home care services will be particularly dramatic since it is in this age range that physical problems occur with greater frequency and greater severity.

I was pleased when I learned that Senator Dodd had called for today's hearing because I believe that thoughtful planning is essential if we are to successfully meet the health needs of our older Americans in the years ahead.

Most of our elderly are able to live relatively independent lives.

Despite common stereotypes, only 1 in 20—that is about 5 percent of all elderly Americans—are in nursing homes.

The overwhelming majority either live with a spouse or live alone or live with their children.

Slightly more than half—51 percent, to be exact—o it was made more readily available or affordable.

Two trends we see in Connecticut reflect the importance of providing supportive services along with shelter; they are the development of congregate housing and life- or continuing-care communities. These are becoming more and more needed and more popular.

Congregate housing typically provides services such as meals and housekeeping. It is for people who can live independently with a certain level of support.

Congregate housing is being developed from the ground up, but it is also appearing in the form of services being added to traditional senior housing complexes.

We have many senior complexes where the residents have aged in place over 10 to 15 years and, now, they really do need more support services.

Life- or continuing-care facilities promise to become an increasingly more popular option for middle-class elderly.

Typically, they provide a residence with an on-premises nursing home, so a person will essentially receive care for life, we hope.

Often, they require substantial sums of money up front—sometimes as much as $60,000—in addition to monthly maintenance fees of approximately $600 to $800.

Beginning next January, my office will begin monitoring such organizations to provide better financial information to consumers about their financial solvency.

But we must do more to make our long-term health care system delivery more responsive to the needs of older Americans.

Connecticut has more than 400 long-term care facilities which, by and large, provide quality care for their residents.

My ombudsman office, which has the responsibility for investigating complaints of this type, handled about 700 problems last year.

Significantly, 85 percent of these complaints, mostly dealing with quality of care, were resolved by working with the administrator.

Thus, I believe we are fortunate to have administrators that are responsive and willing to listen.

Several national items warrant special attention. The Health Care Financing Administration's new nursing home survey process goes into effect this summer.

For the first time, residents will have the chance to participate in a survey of their facility.

Particular attention will be paid to nutritional practices and medication delivery.

This new survey process has the support of the nursing home industry, residents, and advocates for the elderly, alike.

I believe it will improve levels of care throughout the country, and I am pleased to see its acceptance.

Beyond this, the Institute of Medicine has just released a report on nursing homes which outlines guidelines for the delineation of nursing home patients' rights and improving quality of life.

The report proposes to change Federal standards so they measure actual nursing home performances, not just the capacity to perform.

It also focuses on nurses' aides, who provide 90 percent of all direct care to residents.

Preservice training prescribed by the Federal Government would be required before they start work.

Significantly, a number of proposals spawned by this study are already a reality in Connecticut.

We have had a patients' bill of rights for years and, last year, we passed legislation designated to make it more difficult to discriminate against Medicaid patients in nursing homes.

In summation, I feel the quality of long-term care in the State is good, but I am hopeful, with action by the Federal Government, changes proposed by the Institute of Medicine will make it even better.

But institutionalization is not for everyone, as was certainly noted here in the first testimony. In fact, of the estimated 30,000 Connecticut seniors in nursing homes, perhaps as many as 25 percent of them would not need to be there if alternatives were available to them.

Our Promotion of Independent Living Program has done an excellent job of providing in-home social and health services yearly for some 4,300 elderly citizens, by helping them to avoid unnecessary institutionalization.

We expect to increase that number substantially next year.

Our data indicates that between 3 and 7 percent of all elderly have unmet home care needs.

Even with additional State funding for home care and adult day care, we find it hard to provide services to everyone in need.

We must look to the Federal Government to make changes in the types of services for which they will provide reimbursement.

For too long it has been very difficult to receive Medicare and Medicaid coverage for home care.

It has been difficult to obtain waivers to allow Medicaid to pay for community-based care.

Incidentally, the State department of income maintenance has made a request of the Federal Government to approve a Medicaid waiver for prescreening in community-based care situations.

I am very supportive of proposals such as those offered in the past by Senator Bradley of New Jersey and Senator Heinz of Pennsylvania that make it easier for the States to obtain a waiver to allow Medicaid to pay for home care.

Americans on Medicare know how difficult it is to get approval to pay for home care, especially for chronic conditions.

Yet, I would argue that changing circumstances require changes in programs.

It makes no sense to deny a person home care benefits under Medicare, and then have them enter a nursing home and, in a matter of months, go on Government assistance; Medicaid.

A recent New York experience found that 40 percent of all patients paying for nursing home care exhausted their resources within 4 months.

Why not help them sooner with the more appropriate home care services and let them continue to live independently?

Obviously, this would require a significant change in Medicare. We are experiencing changing circumstances now, and people are living longer and need more assistance.

It is our responsibility to do what we can to ensure that we provide our older citizens with the support they need to lead productive, fulfilling lives.

Anything less means that we have not lived up to our commitment made when we accepted our offices and took an oath to faithfully discharge our duties to the best of our abilities.

Thank you very much.

Senator Dodd. Thank you very much.

What I would like to do is just have all the members of the panel comment, and then come back and we will take the questions that we have.

And for those of you who may have some questions, in addition to the ones I ask the panel, if you would write those out, we will have them picked up. And I will get to as many of them as I can at the end of this program.

Dr. Ostfeld.

STATEMENT OF ADRIAN M. OSTFELD, M.D., PROFESSOR OF EPIDEMIOLOGY AND PUBLIC HEALTH, YALE UNIVERSITY SCHOOL OF MEDICINE

Dr. **Ostfeld**. Senator, my remarks are directed toward the size of the need for help for older people living at home.

The information I am giving is based on data from a study of 2,811 older people living in New Haven in their own homes.

The 2,811 were carefully selected so as to be completely representative of all 15,330 people aged 65 and older living in New Haven.

The data are completely applicable to New Haven and, I believe, are also representative for the elderly in all of the State's cities with a population in excess of 100,000.

The study was supported by the National Institute on Aging, enrolled the participants in 1982, and is now in the fourth annual recontact with these participants.

The information I provide is based on lengthy face-to-face contacts with participants in their own homes.

First, what can we say about the life circumstances of these people?

While 69 percent of the white males are now married and 51 percent of black males are now married, only 30 percent white females and 22 percent of black females are now married.

What proportion are earning less than $5,000 per year? Fourteen percent of the white males and 35 percent of black males earn less than $5,000 per year, while 30 percent of white females and 61 percent of black females earn less than $5,000 per year.

About 1 out of every 5 men and about 1 out of every 10 women state they still work regularly at some activity.

About one out of four live alone. About one out of four have no living children. About one out of four have no close relatives, and about one out of four have no close friends.

These categories are not mutually exclusive. There are a sizable proportion of these people who have no one in any category to whom they can turn.

Second, what can we say about the amount and kind of disability in these participants?

About 1 out of 20 older people either is unable to dress him- or herself or needs help to do so. These are people living at home.

About 1 out of 10 cannot walk across a small room or need help in walking across a small room.

About 1 out of 20 is unable to get from a bed to a chair or needs help in getting from a bed to a chair.

About 1 out of 30 is unable to use the toilet or needs help in doing so.

About 1 out of 35 is unable to feed him- or herself or needs help feeding.

About 1 out of 10—but about 1 out of 5 black women—are unable to climb a flight of stairs. About 1 out of 10—but, again, 1 out of 5 black women—are unable to stoop, crouch, or kneel. And about 1 out of 10 is unable to bathe or needs help to do so.

The good news is that three out of four of the people disabled 1 year were either partly recovered or completely recovered from that disability in the following year.

This means that much disability is reversible and that help is needed for a relatively short period of time.

Disability is by no means always permanent, and does not frequently require continuous help.

Third, what can we say about the nature and the frequency of the health problems among these people?

About one out of two has high blood pressure. Just under 50 percent have arthritis. One out of seven has either had cancer or currently has cancer.

One out of seven is diabetic, and one out of nine has had a heart attack. One out of twelve has had a stroke. One out of twenty-five has had a fractured hip. And 1 percent have Parkinson's disease.

In summary, many New Haven elderly are no longer married, live alone in poverty or without living children, close relatives or friends. They need help with day-to-day activities or are unable to carry out these activities at all.

Fortunately, most of the disability is temporary at least in the short run, requiring temporary help.

Finally, there is a considerable burden of chronic disease among all elderly participants.

For some of these diseases, complete recovery is possible. But most older people will need some kind of care for their health problems for the remainder of their years.

The need is great. The time is short. The solutions are beginning to emerge.

Thank you.

Senator **Dodd**. Thank you, Doctor, very much.

[Applause.]

Senator **Dodd**. Ms. Wasik.

STATEMENT OF AUDREY M. WASIK, COORDINATOR, CONNECTICUT COMMISSION ON LONG-TERM CARE

Ms. **Wasik**. Thank you, Senator Dodd.

Distinguished guests, Commissioner Heintz, it is a pleasure to meet with all of you this morning on this important topic.

Health care, for generations, has meant acute care, hospital care.

Today, society is beginning to deal with long-term care. Long-term care will be the major health and social issue of the next four decades.

Already, financial resource needs of long-term care are competing with those of defense, education, energy, and welfare.

It is a fact that nursing homes have been the center of our system of long-term care.

In the late 19th and early 20th centuries, that system consisted of county poorhouses, State mental hospitals, voluntary homes for the aged, early proprietary boarding homes and hospital-affiliated nursing homes.

And, as we know, since those beginnings, legislation providing medical assistance programs for the aged in 1960 and Medicare and

Medicaid in 1965 have all encouraged increased use of and improved nursing home care.

However, what we have today as a system is far from perfect.

Today, we recognize that nursing homes, alone, cannot meet the need of our projected high numbers of elderly in need of care.

We also recognize a large informal family support system trying desperately to access services at home, to keep loved ones at home.

We can no longer ignore their leads. Today, therefore, we are rightly beginning to think in terms of a continuum of care, a long-term care spectrum with access to community-based services and institutional care, as the need arises.

Systems and services, however, develop around available dollars, and the major portion of our public dollars, Medicare and Medicaid, primarily, have had a continual and potent institutional bias, thus leaving us without a balanced system of care, without a system that builds on informal support mechanisms and without a system that seeks affordable care.

Our elderly want options. They do not want to pauperize themselves. They want to be independent. They want to remain at home, and they want affordable care.

How can we achieve a comprehensive and compassionate system?

Of all the Federal programs that provide long-term care, none was originally intended for that purpose, and no explicit national policy for providing or coordinating long-term care services has ever been defined.

Clearly, we need a comprehensive Federal policy framework in the context of which States can elect options to meet their citizens' needs, comprehensive in the sense that all care need is accessible, affordable, and integrated.

We need a system of care that is client need driven, where the needs are assessed first, services selected second and fiscal packaging third.

It is essential that a comprehensive system be available to everyone in need of care with appropriate cost-sharing based on income and resources.

The absence of such a national policy is, in my opinion, our largest gap and our greatest need.

However, let me also focus on other than the issue of policy, itself; briefly, four items.

Education of the public, including assisting the local officials in grasping the complexity and severity of the pending health care and related housing problems is needed.

Suburbia was developed for the young, not the old. We all need help in alternative planning to meet real needs of the elderly.

Exercise and nutrition: We need a new mindset about joint motion and age. We also need to learn so much more about nutrition and special diets.

To make my point, let me share with you the story of Lillian Burhans, which appeared in the Hartford Courant on April 25.

At age 54, she was disabled with arthritis and in constant pain, and had little mobility.

Today, at age 72, after physical therapy and a special nutrition program, she feels strong as an ox and has, for 7 years, conducted exercise classes four times a week at senior centers as a volunteer.

Something exciting is happening out there and, yet, we have such little data.

We need to strongly desire to make Lillian's story unnewsworthy.

As to individual retirement accounts, I must comment. From a long-term care policy perspective, retention of that incentive to save money for our later years leaves the Government and the consumer in a win-win situation.

I very much agree with the Senator's efforts in that area.

Lastly, networking—State and Federal Governments need to network with the private sector regarding finance schemes.

Governor O'Neill's lead, as Senator Dodd has referred to, last week, in forming a commission to study financing of long-term care is an excellent example of a major effort linking government and the private sector.

The Federal Government must also be asking how best can we create incentives and a market for long-term care financing; indeed, a monumental task that must involve us all.

In summary, long-term care needs some major rethinking, not minor tinkering. We need to start with a major structuring of a national policy where institutional and home care are balanced, where social and medical services are balanced and where client/consumer needs prevail over administrative separateness.

And new and innovative programs must become the responsibility of all citizens, all businesses and all levels of government.

We all need to be sensitized. Actually, we need to be inundated with the facts.

Senator, thank you.

[The prepared statement of Ms. Wasik follows:]

STATE OF CONNECTICUT
COMMISSION ON LONG TERM CARE

JULY 7, 1986

OFFICE OF THE COORDINATOR
Audrey M. Wasik

SENATOR DODD, THANK YOU FOR CONVENING THIS PUBLIC HEARING ON "MEETING THE HEALTH NEEDS OF OUR SENIOR CITIZENS: PROVIDING A COMPREHENSIVE AND COMPASSIONATE LONG-TERM HEALTH CARE PROGRAM." AND FOR GIVING ME THIS OPPORTUNITY TO SPEAK.

HEALTH CARE - FOR GENERATIONS HAS MEANT ACUTE CARE - HOSPITAL CARE - TODAY SOCIETY IS BEGINNING TO DEAL WITH, TO LEARN ABOUT AND TO RECOGNIZE OUR EXTENDED CARE SYSTEM - LONG TERM CARE. LONG TERM CARE HAS FOR TOO LONG BEEN THE STEPSISTER OF HEALTH CARE.

LONG TERM CARE - WHAT IS IT AND WHO DOES IT SERVE?

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LONG TERM CARE IS MEDICAL CARE, NURSING CARE, HEALTH CARE, MENTAL HEALTH CARE, AND SOCIAL SERVICES (INCLUDING HOUSING) PROVIDED IN A FRAMEWORK OF REASONABLE COST. AND SUCH A SYSTEM, SHOULD WE DEVELOP A SYSTEM OF CARE, SHOULD ENSURE CONTINUITY, ACCESSIBILITY, ACCOUNTABILITY, AND AFFORDIBILITY - A WORTHY GOAL.

THE CANDIDATES IN NEED OF LONG TERM CARE ARE MAINLY: THE DEVELOPMENTALLY DISABLED, INCLUDING THE RETARDED; THOSE SUFFERING FROM DISABLING, PHYSICAL, MENTAL OR EMOTIONAL TRAUMA; (e.g. VICTIMS OF TRAUMATIC BRAIN INJURY AND ALZHEIMER'S DISEASE) AND THE FRAIL, ELDERLY, MOSTLY 75 YEARS AND OLDER. ALL IN NEED OF ACCESS TO CARE.

LONG TERM CARE WILL BE THE MAJOR HEALTH AND SOCIAL ISSUE OF THE NEXT FOUR DECADES.

ALREADY FINANCIAL RESOURCE NEEDS OF LONG TERM CARE ARE COMPETING WITH THOSE OF DEFENSE, EDUCATION, ENERGY, AND WELFARE.

WE HAVE BEEN A YOUTH ORIENTED CULTURE. WE ARE JUST NOW REALIZING THAT AS A SOCIETY WE MUST CHANGE PRIORITIES TO MEET THE NEEDS OF A FAST GROWING, DIFFERENT AND OLDER POPULATION.

DUE TO ELIMINATION OF ACUTE DISEASES, LIFE IS LONGER, AND CHRONIC DISEASES HAVE REPLACED ACUTE DISEASES AS A MAJOR CAUSE OF DEATH IN THE UNITED STATES. IT IS NO WONDER THEN THAT OUR CLIENTS - RECIPIENTS OF CARE, ARE ALSO AGING. WE ARE NOW SEEING MANY MORE 85+, AND ALONG WITH THIS MUCH OLDER POPULATION WE ARE SEEING OVERALL INCREASED NUMBERS OF SERIOUS CHRONIC CONDITIONS.

LONG TERM CARE - WHERE HAVE WE COME FROM? IT IS A FACT THAT NURSING HOMES HAVE BEEN THE CENTER OF OUR SYSTEM OF LONG TERM CARE. BEFORE WE LOOK AHEAD AT THAT SYSTEM, LET'S STEP BACK AND LOOK AT THE ORIGIN OF LONG TERM CARE - ORIGIN OF NURSING HOMES AND ITS LEGISLATIVE HISTORY.

IN THE LATE 19TH AND EARLY 20TH CENTURIES THERE WERE IN THE UNITED STATES, FIVE TYPES OF FACILITIES THAT ARE CONSIDERED THE ORIGIN OF NURSING HOMES. THESE ARE GENERALLY DESCRIBED BY VOGEL AND PALMER AS:

COUNTY POOR HOUSES
STATE MENTAL HOSPITALS
VOLUNTARY HOMES FOR THE AGED
EARLY PROPRIETARY BOARDING HOMES
HOSPITAL AFFILIATED NURSING HOMES

1) THE COUNTY POOR HOUSES - "ALMS HOUSE", "HOMES" OR "FARMS" WERE OPERATED AND FINANCED BY LOCAL GOVERNMENTS - CHILDREN AND ADULTS OF VARIOUS HEALTH AND FINANCIAL STATUS - POOR - OLD - DISABLED - RETARDED - MENTALLY DISTURBED - ALL PLACED TOGETHER.

DISAPPEARANCE OF POOR HOUSES IN THE 30'S AND 40'S, WAS PARTIALLY DUE TO EFFORTS OF REFORMERS WORKING FOR SPECIALIZED INSTITUTIONS, BUT IT WAS ESPECIALLY DUE TO THE PASSAGE OF SOCIAL SECURITY LEGISLATION IN 1935 WHICH PROVIDED INCOME MAINTENANCE FOR THE AGED AND DISABLED AND PROVIDED THE POSSIBILITY FOR SOME RESIDENTS TO SEEK ALTERNATE LIVING ARRANGEMENTS.

2) STATE MENTAL HOSPITALS - IN THE 1940'S ABOUT 25% OF THE INSTITUTIONALIZED AGED WERE CONFINED TO MENTAL HOSPITALS - OFTEN THE ONLY INSTITUTION OR FACILITY AVAILABLE. EVENTUALLY WITH THE ADVENT OF PSYCHOTROPIC DRUGS AND OTHER DEVELOPMENTS, PATIENTS BEGAN TO BE DISCHARGED. IN THE 60'S AND 70'S ABOUT ONE-HALF OF THE POPULATION OF MENTAL HOSPITALS WAS DISCHARGED - IN RETROSPECT SOME SAY WHOLESALE "DUMPING," MANY LANDING IN OTHER INSTITUTIONS SUCH AS TODAY'S NURSING HOMES - THIS WAS TRUE ALSO IN CONNECTICUT - SUCH PLACEMENT WAS FACILITATED BY THE AVAILABILITY OF FINANCING FOR NURSING HOME CARE.

3) HOMES FOR THE AGED - ESTABLISHED BY IMMIGRANT GROUPS AND VOLUNTARY AND RELIGIOUS ORGANIZATIONS, e.g. LUTHERAN, METHODIST, AND JEWISH ORGANIZATIONS IN THE LATE 19TH AND EARLY 20TH CENTURIES, ESTABLISHED TO PROVIDE SHELTER AND MAINTENANCE. THEY GRADUALLY TOOK ON ADDITIONAL SERVICES, AND MANY EVOLVED INTO THE VOLUNTARY NON-PROFIT SECTOR OF THE NURSING HOME INDUSTRY TODAY.

4) EARLY PROPRIETARY BOARDING HOMES - LATE 19TH AND EARLY 20TH CENTURIES - DESIGNED TO PROVIDE ROOM, BOARD, AND PERSONAL CARE - OFTEN A CONVERTED ONE-FAMILY HOME. AS RESIDENTS AGED, CARE INCREASED, AND MANY BECAME TODAY'S PROPRIETARY NURSING HOMES. (THE AGING IN PLACE PHENOMENA THAT WE ARE AGAIN SEEING TODAY IS SENIOR HOUSING WHICH PROVIDES NO SERVICES.)

5) THE 5TH COMPONENT OF NURSING HOME HISTORY AND YESTERDAY'S LONG TERM CARE SYSTEM IS THE HOSPITAL AFFILIATED NURSING HOME, ESTABLISHED BY HOSPITALS IN THE 20TH CENTURY AS AN ADJUNCT TO HOSPITAL SERVICES. THESE ESTABLISHMENTS REFLECT THE INCREASED SPECIALIZATION OF HOSPITALS AS A CENTER FOR TREATMENT OF ACUTE ILLNESSES; CONSTRUCTION OF SUCH NURSING HOMES WAS ENCOURAGED BY THE HILL-BURTON ACT.

AND AS WE KNOW, SINCE THEN, LEGISLATION-PROVIDING IN 1960, MEDICAL ASSISTANCE PROGRAMS FOR THE AGED - IN 1965, MEDICARE AND MEDICAID - HAVE ALL ENCOURAGED INCREASED USE OF AND IMPROVED NURSING HOME CARE.

WHAT HAS EVOLVED AS TODAY'S NURSING HOME IS A FAR CRY FROM THE POOR HOUSES WHERE CLIENTS WERE REFERRED TO IN LEGISLATION AS "INMATES OF PUBLIC INSTITUTIONS." TALK ABOUT A DEVALUED POPULATION!!

HOWEVER, WHAT WE HAVE AS A SYSTEM IS FAR FROM PERFECT, AND IF WE - NATIONAL AND STATE GOVERNMENTS - WERE TO DO IT ALL OVER AGAIN REALIZING WHAT WE NOW KNOW - WE WOULD HAVE DONE YESTERDAY WHAT WE ARE DOING TODAY.

TODAY WE RECOGNIZE THAT NURSING HOMES ALONE CANNOT MEET THE NEEDS OF OUR PROJECTED HIGH NUMBERS OF ELDERLY IN NEED OF CARE. THAT IS, TO SAY IT ANOTHER WAY, IT IS RECOGNIZED THAT SOCIETY CANNOT AFFORD A NURSING HOME BED FOR EVERYONE WHO COULD OR WOULD APPROPRIATELY OR INAPPROPRIATELY USE IT.

WE ALSO, SOME OF US ANYWAY, RECOGNIZE A LARGE INFORMAL FAMILY/NEIGHBORS SUPPORT SYSTEM TRYING DESPERATELY TO ACCESS SERVICES AT HOME, TO KEEP LOVED ONES AT HOME. I DISAGREE WITH THOSE WHO SAY THAT THE INFORMAL SUPPORT NETWORK HAS DISAPPEARED. TO THE CONTRARY RESEARCH HAS INDICATED THAT 60-80% OF CARE IS GIVEN BY FAMILY AND FRIENDS. I AGREE WITH THAT AND FEEL WE CAN NO LONGER IGNORE THEIR NEEDS.

TODAY, THEREFORE, FOR WHATEVER REASON, WE ARE RIGHTLY BEGINNING TO THINK IN TERMS OF A CONTINUUM OF CARE - A LONG TERM CARE SPECTRUM WITH ACCESS TO COMMUNITY BASED SERVICES AND INSTITUTIONAL CARE AS THE NEED ARISES..

SYSTEMS AND SERVICES HOWEVER, DEVELOP AROUND AVAILABLE DOLLARS AND ALTHOUGH EXPERTS SINCE THE '70'S HAVE CLEARLY STATED THE VALUE OF HOME CARE AND COMMUNITY BASED SERVICES STILL THE MAJOR PORTION OF OUR PUBLIC DOLLARS (MEDICARE AND MEDICAID) HAVE HAD A CONTINUAL AND POTENT INSTITUTIONAL BIAS. THUS LEAVING US WITHOUT A BALANCED SYSTEM OF CARE, WITHOUT A SYSTEM THAT BUILDS ON INFORMAL SUPPORT MECHANISMS AND WITHOUT A SYSTEM THAT SEEKS AFFORDABLE CARE. RATHER TODAY WE HAVE A SYSTEM THAT ENCOURAGES "SPEND DOWN" AND NURSING HOME PLACEMENT. WE HAVE A SYSTEM INFLEXIBLE, A SYSTEM WITH TOO FEW OPTIONS.

A BALANCED SYSTEM, A COMPREHENSIVE SYSTEM WILL ALWAYS INCLUDE A NURSING HOME, AN INSTITUTIONAL COMPONENT, BUT OUR ELDERLY WANT OPTIONS. THEY DO NOT WANT TO PAUPERIZE THEMSELVES. THEY WANT TO BE INDEPENDENT, THEY WANT TO REMAIN AT HOME. THEY WANT AFFORDABLE CARE.

INCREASED INTEGRATED COMMUNITY BASED SERVICES WILL OF COURSE NOT ALWAYS MEET OR ANSWER ALL THOSE WANTS FOR EVERYONE BUT I DO BELIEVE THAT A COMPREHENSIVE SYSTEM CAN PROVIDE AFFORDABLE OPTIONS FOR A LARGE NUMBER OF ELDERLY.

HOW CAN WE ACHIEVE A COMPREHENSIVE AND COMPASSIONATE SYSTEM?

AS STATED IN A "STATEMENT ON LONG TERM CARE POLICY" BY THE NATIONAL COUNCIL OF STATE HUMAN SERVICE ADMINISTRATORS

QUOTE:

"A BRIEF HISTORY OF LONG-TERM CARE POLICY WILL HELP ILLUSTRATE ITS FRAGMENTED NATURE. OF ALL THE PROGRAMS THAT PROVIDE LONG-TERM CARE, NONE WAS ORIGINALLY INTENDED FOR THAT PURPOSE. MEDICARE WAS DESIGNED TO PROVIDE ACUTE CARE HOSPITAL AND PHYSICIAN SERVICES FOR THE ELDERLY, THOUGH THE MYTH CONTINUES TODAY THAT MEDICARE WILL PAY FOR EXTENDED NURSING HOME STAYS. MEDICAID WAS ENACTED TO PROVIDE HEALTH CARE TO CERTAIN LOW-INCOME FAMILIES AND INDIVIDUALS; IT WAS EXPECTED TO REMAIN RELATIVELY SMALL IN SIZE. THE OLDER AMERICANS ACT, WHILE PROVIDING SERVICES AND NUTRITION PROGRAMS FOR THE ELDERLY, HAS ONLY RECENTLY HAD A MANDATE TO EVALUATE ITS EFFORTS IN THE CONTEXT OF A LARGER, COOPERATIVE LONG-TERM CARE SYSTEM. THE SOCIAL SERVICE BLOCK GRANT, TITLE XX OF THE SOCIAL SECURITY ACT, HAS RECOGNIZED THE AGED AS ONE PART OF THE POPULATION NEEDING SERVICES; BUT AGAIN NO EXPLICIT POLICY FOR PROVIDING OR COORDINATING LONG-TERM CARE SERVICES HAS EVER BEEN DEFINED...."

STATE GOVERNMENTS HAVE ALSO BEEN LACKING IN NOT RECOGNIZING A NEED TO COORDINATE ON A STATE LEVEL THESE VALUED FEDERAL PROGRAMS. CONNECTICUT HAS TAKEN A GIANT STEP TO CORRECT THIS. THE COMMISSION ON LONG TERM CARE HAS ADOPTED POLICY GOALS ON COMMUNITY BASED SERVICES FOR THE ELDERLY THAT CROSS STATE AGENCY LINES AND IS DESIGNED TO INSURE COORDINATION.

THE NATIONAL COUNCIL OF STATE HUMAN SERVICE ADMINISTRATORS ALSO STATES: "THE FACT THAT MEDICAID, AS AN ENTITLEMENT HAS BEEN ALLOWED TO EXPAND, BUT THE SOCIAL SERVICES BLOCK GRANT AND OLDER AMERICANS ACT FUNDS HAVE REMAINED RELATIVELY SMALL AND LIMITED, HAS CREATED A CLEAR BIAS IN OUR PUBLIC PROGRAMS TO PROVIDE INSTITUTIONAL CARE RATHER THAN COMMUNITY CARE AND TO PROVIDE CARE BASED ON A MEDICAL MODEL RATHER THAN A SOCIAL MODEL.

WE ARE NOW ASKING WHEN IS IT APPROPRIATE TO USE A MEDICAL MODEL IN DESIGNING A DELIVERY SYSTEM AND WHEN IS A SOCIAL MODEL MORE APPROPRIATE?"

CLEARLY WE NEED A COMPREHENSIVE FEDERAL POLICY FRAMEWORK IN THE CONTEXT OF WHICH STATES CAN ELECT OPTIONS TO MEET THEIR CITIZEN'S NEEDS.

COMPREHENSIVE, NOT IN THAT IT COVERS ALL ASPECTS OF CARE, BUT COMPREHENSIVE IN THAT ALL CARE NEED IS ACCESSIBLE, AFFORDABLE AND INTEGRATED. NOT CATEGORICAL, NOT BY PROFESSION OR DISCIPLINE, OR FUNDING SOURCE.

WE NEED A SYSTEM OF CARE THAT IS CLIENT NEED DRIVEN, WHERE THE NEEDS ARE ASSESSED FIRST, SERVICES SELECTED SECOND AND FISCAL PACKAGING THIRD.

IT IS ESSENTIAL THAT A COMPREHENSIVE SYSTEM BE AVAILABLE TO EVERYONE IN NEED OF CARE WITH APPROPRIATE COST SHARING BASED ON INCOME AND RESOURCES. CARE CANNOT BE LIMITED OR STRUCTURED JUST FOR ONE ECONOMIC LEVEL. HOW ELSE CAN WE HELP TO AVOID SPEND DOWN AND MEET REAL HEALTH AND SOCIAL SERVICE NEEDS?

AS YOU CAN SEE I STRONGLY FEEL THE NEED FOR A NATIONAL POLICY THAT ADDRESSES COORDINATION OF SYSTEMS, DEVELOPMENT OF A CLIENT NEED DRIVEN SYSTEM, AND THE BALANCING OF INSTITUTIONAL VS. COMMUNITY BASED SERVICES. THE ABSENCE OF THIS POLICY IS OUR LARGEST GAP AND OUR GREATEST NEED.

HOWEVER, LET ME ALSO FOCUS ON OTHER THAN ISSUES OF POLICY ITSELF AND ONTO SOME PROGRAM SPECIFICS AND SUGGESTIONS.

EDUCATION OF THE PUBLIC INCLUDING ASSISTING LOCAL OFFICIALS IN GRASPING THE COMPLEXITY AND SEVERITY OF THE PENDING HEALTH CARE AND RELATED HOUSING PROBLEMS IS NEEDED. SUBURBIA WAS DEVELOPED FOR THE YOUNG NOT THE OLD. THE NEED FOR LIVING ARRANGEMENTS WITH SUPPORT SERVICES AMONG OTHER ALTERNATIVES, MUST BE REALIZED BY ALL GOVERNMENTS. WE ALL NEED HELP IN ALTERNATIVE PLANNING TO MEET REAL NEEDS OF THE ELDERLY. WE NEED TO MORE ACTIVELY SHARE OUR KNOWLEDGE WITH THE GENERAL PUBLIC AND OUR OFFICIALS.

EXAMPLES OF LIVING ARRANGEMENTS INCLUDE FOSTER CARE PROGRAMS FOR THE ELDERLY, LIFE CARE/CONTINUING CARE COMMUNITIES. SUCH COMMUNITIES ARE TAKING ON MANY FORMS - PROVIDING PRIMARILY SECURITY AND ACCESS TO HEALTH CARE.

SOME COMMUNITIES ALLOW ELDERLY TO RENT ROOMS TO AVOID THE PROPERTY RICH CASH POOR PHENOMENA THEREBY ALLOWING INCREASED CASH FLOW SO INDIVIDUALS CAN AFFORD CARE IN THEIR HOMES.

MOTHER-IN-LAW APARTMENTS - NOW SEEN MORE FREQUENTLY

CONGREGATE HOUSING PROVIDING LIVING ARRANGEMENTS WITH SUPPORT SERVICES

ALL TOWNS NEED TO BE AWARE OF THESE IMPORTANT HOUSING ARRANGEMENTS AND NEED TO KNOW HOW BEST TO PLAN FOR THEIR ELDERLY. PRIVATE SECTOR ATTEMPTS TO INTRODUCE NEEDED HOUSING ARRANGEMENTS NEED OFTEN TO BE TAKEN MORE SERIOUSLY.

MEDICARE & MEDIGAP - EDUCATION TO THE FACTS OF INSURANCE COVERAGE. WE NEED TO BETTER UNDERSTAND WHAT MEDICARE DOES NOT COVER. WE NEED TO DISPEL THE MYTH OF MEDICARE. SENIORS ESPECIALLY NEED ADVICE ON PURCHASING INSURANCE. PURCHASE OF DUPLICATE MEDIGAP POLICIES IS CASH WASTE AND YET A COMMON OCCURRENCE.

RESPITE CARE - A WAY TO BUILD ON THE INFORMAL CARE NETWORK. SOME FAMILIES ARE DESPERATELY IN NEED OF RESPITE CARE. THIS CAN BE IN THE FORM OF ADULT DAY CARE OR ASSISTANCE AT HOME OR EVEN TEMPORARY NURSING HOME CARE. RESPITE CAN CERTAINLY HELP TO AVOID OR DELAY INSTITUTIONALIZATION.

ALZHEIMERS - SPOUSES AND FAMILIES OF ALZHEIMERS VICTIMS SUFFER AS MUCH AS THE CLIENT. BOTH COMMUNITY BASED SERVICES AND PROPER INSTITUTIONAL CARE IS DESPERATELY NEEDED FOR THIS POPULATION. I AM SERIOUSLY CONCERNED ABOUT MEETING THE NEEDS OF CAREGIVERS AND CLIENTS AND PHYSICIANS REGARDING THIS DISEASE. IF I HAD TO SINGLE OUT ONE DISEASE THAT IS IMPACTING THE GREATEST ON THE LONG TERM CARE SYSTEM I WOULD CERTAINLY CITE ALZHEIMERS.

CASE MANAGEMENT - THERE IS A NEED FOR GOVERNMENT TO PROMOTE CASE MANAGEMENT FOR ALL THOSE WITH TROUBLE ACCESSING THE LONG TERM CARE SYSTEM AND SEEKING COST EFFECTIVE AND AFFORDABLE CARE. ACCESSING NECESSARY CARE FOR OUR ELDERS CONTINUES TO REMAIN A MOST SERIOUS PROBLEM REGARDLESS OF INCOME LEVEL.

EXERCISE AND NUTRITION - WE NEED A NEW MIND SET ABOUT JOINT MOTION AND AGE. WE ALSO NEED TO LEARN SO MUCH MORE ABOUT NUTRITION AND SPECIAL DIETS. TO MAKE MY POINT, LET ME SHARE WITH YOU THE STORY OF LILLIAN BURHANS WHICH APPEARED IN THE HARTFORD COURANT APRIL 25TH. AT AGE 54 SHE WAS DISABLED WITH ARTHRITIS AND IN CONSTANT PAIN. TODAY AT AGE 72 AFTER PHYSICAL THERAPY AND A SPECIAL NUTRITION PLAN SHE FEELS STRONG AS AN OX AND HAS FOR 7 YEARS CONDUCTED EXERCISE CLASSES 4 TIMES A WEEK AT SENIOR CENTERS AS A VOLUNTEER! SOMETHING EXCITING IS HAPPENING OUT THERE AND YET WE HAVE SUCH LITTLE DATA. WE NEED TO STRONGLY DESIRE TO MAKE LILLIAN'S STORY UN-NEWSWORTHY.

Exercise Enthusiast Overcomes Ailments With Determination

By MIRIAM SILVER
Courant Staff Writer

EAST HARTFORD — As she approaches her 73rd year, Lillian Burhans has the body of a 16-year-old and the mind of a knowledge-hungry college student.

Virtually crippled by osteoarthritis and debilitating back problems 10 years ago, Burhans has practically redesigned her body and mind with a determination unusual at any age.

Now she teaches exercise four days a week to senior citizens, devours books on anatomy and physical fitness and — despite a pinched nerve in one foot — feels better than she has in her life.

"If I didn't have the problem with my foot, I don't think there'd be a healthier person," Burhans said.

For seven years, she has been sharing her knowledge and good fortune with about 500 senior citizens who have come to the free aerobics classes she teaches four times a week.

Saturday, Mayor Robert F. McNulty will toast Burhans during a Community Volunteer Fest marking national volunteer week, which began last Sunday.

The mayor's commendation, to be presented at 10 a.m. in McAuliffe Park, characterizes Burhans as "the living embodiment of volunteerism, unparalleled in her sincere altruism."

At 5-foot-3 and 109 pounds, Burhans' small frame belies her intensity. "I'm strong as an ox. I can do anything I want to do," she said proudly. "My doctor says I have the body of a 16-year-old."

When she was 54, while working as a blueprint supervisor at Pratt & Whitney Aircraft, Burhans was a wreck. She could not stand up straight, and constant pain wracked most of her body.

"I felt I was doomed. I was afraid I wouldn't walk again."

See Enthusiast, Page B2

B2 THE HARTFORD COURANT Friday, April 25, 1986

Enthusiast Feels Her Best at 72

Continued from Page B1

Michael Lennahan / The Hartford Courant

Lillian Burhans uses a chair during an exercise routine at an East Hartford senior center.

Burhans said. "The arthritis will give you so much pain, you will wish you was dead. That's how you feel."

She began looking into physical therapy, and it turned her life around.

"It seemed the therapy did more good for me than the medication. So I became interested," she said.

In 1979, Burhans began reading books on nutrition, physical fitness and therapy "from cover to cover." She started taking classes in area hospitals with teachers from the Holistic Life Foundation, a non-profit educational foundation based in Montana.

Shortly afterward, she began teaching other senior citizens what she had learned.

Two years into her studies and exercise programs, the physical improvements were obvious. Burhans stopped wearing a microceptor, a battery-powered electronic devise attached to both legs to short-circuit nerves. The anti-inflammatory injections she had been receiving twice a month were cut back to four times a year.

"The more I did with physical therapy and exercising, the better I felt," she said.

Burhans' doctor, Arnold Goldenberg, said that when he first saw her, she was a "very frail and sickly type woman. She looked like someone heading for a neurological disorder."

But she began making remarkable strides through the exercise program, Goldenberg said.

In 1976, after 23 years with Pratt & Whitney, Burhans retired from the jet-engine manufacturer, joining her husband, Theodore, who retired in 1971.

Theirs is an active life. He is a beekeeper, tending hives at his home on Elm Street as well as on farms in other towns.

Burhans, the mother of two stepchildren and grandmother of five, said she goes stir-crazy on Sundays, her day off from volunteer work.

"Sundays we sit around, read the paper. I wind up going upstairs and exercising. I just can't take it," she said.

Burhans says she is devoted to her volunteer work as an exercise teacher because it is a service she wishes she had when she was in pain. Every week, she teaches at four locations, including the two seniors' centers in town.

Using the principle "What you don't move, you lose," Burhans stands on a stage in front of 40 to 70 seniors citizens and offers them isometrics, stretches, mild aerobics and jokes.

Her biggest accomplishment since she began teaching classes in 1979 is William Bray, a 71-year-old East Hartford man who last summer suffered a massive stroke that left him speechless and paralyzed on one side.

Burhans told Bray's wife, Irene, who is a student and friend, that she would like to help him. Two times a week, she led him through exercises. Now Bray, whom doctors had said would have to use a wheelchair, is walking around his house with a cane.

"The greatest reward I've had is seeing Bill Bray walk again," Burhans said.

Her students talk about the fun they have in her class, about how the neck pains have gone away, and how they can wear smaller dress sizes again.

"I don't get enough exercise, and I was getting a little tummy here," said Eileen Arbuckle, 72, a student in Burhans' class at the South End Senior Center.

"Also, I have arthritis in my hips and hands, and this has really helped me a great deal," Arbuckle said. "Look how wonderful [Burhans] looks. And she's so limber."

It's all quite rewarding for Burhans, who likes to think that fewer senior citizens need to rush into nursing homes, thanks to her help.

"I feel they're getting more and more away from that because they are becoming educated in what's out there for them and not becoming a burden on themselves and their family. Many people feel they've stayed in their own homes longer because they stay active," Burhans said.

"Seniors citizens in East Hartford are the healthiest people in town," she said.

INDIVIDUAL RETIREMENT ACCOUNTS HAVE THE POTENTIAL TO PROVIDE THE AVERAGE AMERICAN WITH ENORMOUS RESOURCES TO USE ON LONG TERM CARE. A DECISION TO RETAIN OR ELIMINATE THIS TAX OPTION IS CURRENTLY PENDING. ARE WE SHORTSIGHTED AS A NATION IN CONSIDERING THE TAX REVENUE COMPARED TO THE POTENTIAL IMPACT ON INDEPENDENT CARE SUCH MONIES COULD PROVIDE?

SENATOR, YOU WERE RIGHT TO PROPOSE AN AMENDMENT TO RETAIN THE CURRENT TAX DEDUCTIONS TIED TO IRAS. THE CONFERENCE COMMITTEE CURRENTLY CONSIDERING THE HOUSE AND SENATE VERSIONS SHOULD RETAIN THE CURRENT TAX INCENTIVE TO SAVE MONEY. FROM A LONG TERM CARE POLICY PERSPECTIVE, RETENTION OF THAT INCENTIVE LEAVES THE GOVERNMENT AND THE CONSUMER IN A WIN-WIN SITUATION.

AND LASTLY NETWORKING

STATE AND FEDERAL GOVERNMENTS NEED TO NETWORK WITH THE PRIVATE SECTOR REGARDING FINANCE SCHEMES. GOVERNOR O'NEILL'S LEAD LAST WEEK IN FORMING A COMMISSION TO STUDY FINANCING OF LONG TERM CARE IS AN EXCELLENT EXAMPLE OF A MAJOR EFFORT LINKING GOVERNMENT AND THE PRIVATE SECTOR. THE FEDERAL GOVERNMENT MUST ALSO BE ASKING HOW BEST CAN WE CREATE INCENTIVES AND A MARKET FOR LONG TERM CARE FINANCING. INDEED A MONUMENTAL TASK THAT MUST INVOLVE THE FEDERAL GOVERNMENT.

IN SUMMARY, LONG TERM CARE NEEDS SOME MAJOR RETHINKING. NOT MINOR TINKERING. WE NEED TO START WITH A MAJOR STRUCTURING OF A NATIONAL POLICY WHERE INSTITUTIONAL AND HOME CARE ARE BALANCED, WHERE SOCIAL AND MEDICAL SERVICES ARE BALANCED AND WHERE CLIENT/CONSUMER NEEDS PREVAIL OVER ADMINISTRATIVE SEPARATENESS. AND NEW AND INNOVATIVE PROGRAMS MUST BECOME THE RESPONSIBILITY OF ALL CITIZENS, ALL BUSINESSES AND ALL LEVELS OF GOVERNMENT. WE ALL NEED TO BE SENSITIZED. ACTUALLY WE NEED TO BE INUNDATED WITH THE FACTS.

STABILITY IS THE STRONGEST ALLY OF CHANGE. OUR SYSTEM IS CHANGING MORE BY OUTSIDE OR EXTERNAL INFLUENCE THAN A STABLE DIRECTED STRATEGIC PROCESS SPECIFIC TO LONG TERM CARE - IAPPRECIATE THE OPPORTUNITY THIS MORNING TO DESCRIBE WHAT I PERCEIVE TO BE THE MISSING LINK IN BUILDING A COMPREHENSIVE AND COMPASSIONATE SYSTEM OF CARE. A SPECIFIC FEDERAL POLICY INITIATIVE AND POLICY FRAMEWORK AROUND WHICH WE CAN FUNCTION.

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Senator Dodd. Thank you very much.

[Applause.]

Senator Dodd. Ms. Daubert, we are glad, again, to have you here.

STATEMENT OF ELIZABETH A. DAUBERT, EXECUTIVE DIRECTOR, THE CONNECTICUT ASSOCIATION FOR HOME CARE, INC.

Ms. Daubert. Good morning. Thank you very much, Senator Dodd and distinguished guests.

I am providing testimony on behalf of the majority of organized providers of public care services in the State.

Currently, 121 agencies, such as Visiting Nurse, public health nursing agencies, hospital-based home care programs, homemaker home health aide agencies, private nonprofit and proprietary agencies, are licensed by the Connecticut Department of Health Services to provide home health care services.

State licensure has been in existence since 1979. Its purpose is to ensure that all organized providers meet strict quality of care standards.

Connecticut was one of the first States to enact a licensure law.

Eighty-five—or 70 percent of the licensed agencies here—are members of the Connecticut Association for Home Care.

Our members, several of whom have been providing home care services to ill and frail elderly individuals for almost 100 years, have a rich history of experience and public service.

Last year, our members provided more than 2½ million units of both traditional and nontraditional home care services to approximately 65,000 individuals.

Of the 2½ million units, 2.1 million traditional service units, such as nursing, physical, speech and occupational therapy, medical/social work and medical supplies were provided, while the remaining 491,000 units consisted of nontraditional or social-support services, such as homemaker, Chore, Companion, Friendly Visitor, Meals on Wheels, screening and counseling sessions at senior citizen and day care centers and respite care programs.

In addition to the services provided by our members, home care services are also provided by 36 other organizations.

Another segment of the home care delivery system is the care provided by the informal family member, friend or individual privately employed by patients and families.

Although no hard data exists, the amount of informal caregiving is, indeed, significant.

The Traveler's Insurance Co. recently surveyed their employees to determine the incidence. Data gathered during that study indicated that approximately 28 percent of Traveler's employees spent on an average of 16 hours a week providing care to an elderly relative or friend.

In addition to that, 8 percent of their employees spent 35 or more hours a week caring for an elderly person.

Every city and town in our State is served by at least one licensed home health agency. While the seven traditional home care services are available in all communities, there is considerable unevenness or gap in the availability of social support services.

The lack of these services, especially homemaker, companion, chore and respite care, is, I believe, the greatest weakness in our State's home care delivery system.

Hospital discharge planners repeatedly say their most difficult problem is finding homemaker, chore, companionship for the patient, respite care for families and meals on wheels.

This scarcity is not caused by multiple complex factors. Rather, the reason why the needs of our seniors for social support services are not being met is, quite simply, a lack of sufficient public and private funds to pay for these services.

Agencies cannot employ or retain adequate numbers of professional and support staff unless they can generate sufficient revenue to meet their weekly payroll.

Elderly individuals or family members cannot hire private individuals because they do not have sufficient incomes to pay for service out of their own pockets.

The Medicare program is a health program in the narrowest sense of the word.

With the exception of its renal dialysis and hospice benefits, Medicare coverage is confined to short-term, acute episode of illness.

According to the National Center for Health Services Research, in 1984, Medicare beneficiaries who used home care benefits received an average of only 22 visits per individual.

By the time figures for 1985 and 1986 are available, the more than 30 restrictions in Medicare-covered services which the current Federal administration has levied on home health providers during the past 18 months, those 22 visits should be reduced to somewhere in the mid- to the low-teens.

The Health Care Financing Administration is systematically dismantling the home health benefit portion of the Medicare Program while, at the same time, its DRG system is causing elderly citizens to leave hospitals sooner and with greater needs for assistance at home.

The availability of long-term care insurance policies is not only meager, but long-term coverage for home care is even more rare than coverage for long-term care in nursing homes.

Even though the Medicaid does provide some coverage for long-term care, for the most part, its home care package is quite limited.

Except for the Medicaid waiver project in Fairfield County, homemaker, handyman, chore, respite care and companion services are not routinely covered.

Many of our seniors are reluctant to apply for Medicare because, to them, it is a welfare program or it means having a lien placed upon their prized possession, their home.

In their minds, the stigma attached to accepting welfare would destroy their independence and their self-worth.

They would prefer—and often do—go without essential services rather than to apply for title 19.

Although the picture is far from bright here in Connecticut, the Department on Aging's home care program does provide social support services.

Even though Commissioner Klinck is creative in administering this program, the present and growing demand for support services by our mushrooming elderly population far exceeds the limited dollars allocated to this program.

The care of the increasing number of chronically ill and frail elderly in a manner which meets their needs, allows them to retain their dignity and, yet, considers limited financial and service resources is one of the most pressing problems facing us all.

There is no easy answer or quick solution which will improve our current nonsystem of delivering long-term care services either in Connecticut or in the country.

Solutions are possible, however, if the public and private sectors, as well as society at large, work together.

First and foremost, the Federal Government needs to develop and mandate the implementation of a clear definition of long-term care.

Furthermore, the provision of home care services must be an integral part of this definition.

For far too long, Federal and State elderly service programs have limited the term "long-term care" to essentially mean care in a nursing home.

Second, home health and skilled nursing home benefits, under the Medicare Program, needs to be expanded or a system of national health insurance for our over 65-year-old population, which includes a full range of professional and social support home care services, needs to be enacted. Anything less is just a stop-gap measure.

Third, criteria all health providers must meet to obtain any Federal and State funding should require and include payment for case management and coordination of services, two absolutely essential components for any long-term care delivery system.

Fourth, public policy needs to be developed which will help families care for their older relatives, such as tax incentives or stipends to be used for direct payment for care.

Fifth, public policy needs to be developed which ensures creation of home care programs which are based on a realistic assessment of the needs of patients and the activities required to meet those needs, rather than around categorical funding sources.

Medicare created the title "home health aide." Title XX created the term "chore worker" and the "in-home supportive services worker," while other Federal funding sources created the term "homemaker."

In many patient situations, narrow definitions of worker tasks are impossible, and they are confusing; they are not cost-effective. And, in some cases, they may even be unsafe.

For example, if a homemaker or chore person is in a patient's home but can only prepare a regular diet, not bland, diabetic, or low-salt meal, must the homemaker or the chore person refuse to give the hungry patient anything to eat because the funding source defines this task as a home health aide duty and the home health aide does not have to be there that day?

Or does the chore person or homemaker leave an elderly person in a bathtub because, according to rigid regulations, they are not allowed to assist people out of bathtubs?

This, unfortunately, is the sad state of affairs of our bureaucratic regulatory system.

Another recommendation I suggest is the mobilization of private-sector volunteer groups, similar to the neighborhood crime watch system, to act as advocates, as information experts concerning the availability of community resources which exist in a community to help our elderly maintain their independence in their own homes.

Seventh, providers of home care services should be encouraged, through the availability of Federal grant moneys, to be more responsive to the changing needs of our elderly citizens.

Existing resources should be used where appropriate to provide services, thereby fostering community involvement and avoiding duplication.

And, finally, insurance companies should be encouraged to develop and market long-term care policies which include reasonable nursing home and home care benefit packages.

Thank you very much, Senator Dodd, for inviting me to present testimony at this hearing, and I commend you for bringing this Senate field hearing to Connecticut.

[Applause.]

Senator DODD. Thank you very much for that comprehensive testimony. The seven points are worthwhile.

I would like to get copies, if I could, of your testimony.

We have it on the record here permanently. But if you have any extra copies of it around, leave us one that you have, and I will see that you get back your originals.

Ms. Quinn, again, we thank you for coming.

STATEMENT OF JOAN QUINN, PRESIDENT, CONNECTICUT COMMUNITY CARE, INC.

Ms. QUINN. Thank you, Senator. Good morning. My name is Joan Quinn. I am president of Connecticut Community Care, a statewide case management agency which serves approximately 5,000 elderly clients per month in Connecticut.

We are under contract with the State Department on Aging to run the Promotion of Independent Living Program, which is a home care program and, since 1983, have run the pilot Medicaid community-based prescreening waiver program for the State Department of Income Maintenance in Fairfield County in seven acute-care hospitals.

We also receive money from five area agencies on aging in Connecticut, as well as corporations, foundations, and individuals.

In addition, clients and their families whom we have cared for contributed approximately $1.825 million toward the cost of their services in the past year.

This is without ever sending a bill to the clients, and I think that the dollar amount contributed is a very impressive number.

In addition to trying to coordinate the care system on behalf of the individual, you can imagine how we have to try to coordinate the fiscal system on behalf of the individual to pay for the care.

During the past fiscal year for 9 months, July 1, 1985 to March 31, 1986, 24 percent of our clients had a length of stay of 37 months or longer on our program.

In addition, our principal reasons for termination were death, 45 percent; nursing home placement, 40 percent; clients moving out of the State, approximately 6 percent. Other reasons account for the remaining percentages.

So, CCCI is providing community services for a very frail population of older adults, the majority of whom are generally on the program for 3 years or longer.

As we measure those older adults in terms of their functioning abilities, we find them similar and/or more disabled than elderly people residing in nursing homes.

So, there is the opportunity, given the resources and the ability to manage the system, for older adults to stay at home, often in very frail conditions.

Given that option, most of them are very willing to contribute toward the cost of their care, if they are able to do so.

I am very concerned about a comprehensive, community-based long-term care strategy and program for this State as well as for the country.

Although the State, as a whole, is generally service rich, there is tremendous and dramatic variation in the availability of service in each of the major geographic regions of the State.

For instance, services might be plentiful in a town like Waterbury, and totally absent in towns a 30-minute drive away.

Serving clients in their own homes with appropriate economical services is a significant challenge.

One of the most important aspects, in terms of coordination of long-term care services is that service coordination efforts must be associated with a prescriptive process that encourages older adults to be independent and also encourages their families to continue supporting them.

Each categorical provider type has a caring network which may overlap other provider networks, but there is no coordination of these multiple networks.

The family/older client then is left to struggle with trying to find the services that they need in the multiple service system often at a time when they are in crisis; they do not have much opportunity for shopping around because they usually need the service immediately.

Connecticut is fortunate, I feel, to have the case management system.

There are many systems in other States that are developing as well. One of our primary focuses is to seek out and provide the most appropriate service, using existing service providers, to meet individual long-term care needs.

With regard to service availability, no one agency can do 100 percent of the job 100 percent of the time.

It makes no difference whether the agency is located in an urban or rural area.

I feel there is the need to develop provider networks but, currently, there is no incentive to create these networks.

The development of provider networks to integrate with family support systems is hard work, which no third-party payor would recognize at this point in time.

In addition, the focus of public and private reimbursement is, as referred to previously, on acute care and very short-term restorative assistance, which is very expensive. There is minimal coverage for preventive services of any type.

How can the Federal Government assist in the development of a long-term care system?

As previously stated, the Federal Government is like a large insurance company that pays for acute, episodic care. They have a political risk pool, as opposed to a premium risk pool.

If the Federal Government became the principal funder of long-term care, I would worry that we might have a second-class system because the Government, historically, has been in the business of transfer benefits from taxes to social services or medical services. Anytime there is any alteration in that transfer formula, it definitely has an impact on the client, as we are seeing with the Medicare system now.

Therefore, I do not feel the Federal Government can be the sole supporter of long-term care services. It needs to act as a catalyst for the private insurance companies to begin to involve them in the development of long-term care insurance coverage, thereby sharing the risk.

I think this is an appropriate way to go just for the sheer numbers of older adults that we have seen for some time.

Long-term care insurance coverage should be mandatory and should be started while an employee is still working in their younger years so that they can build up enough insurance equity to service them when and if they need long-term care services, in their old age.

Finally, there has been much rhetoric, I feel, especially by the Health Care Financing Administration, that utilization and service cost information is not available to begin this mutual activity of long-term care product development.

Yet, since 1974, there have been long-term care demonstration projects around the country with significant research data that answered many questions in this area and would be very helpful in developing long-term care insurance products.

We, as a country—this State included—are in a period where action between the public and private sector is imperative if we want to help older and disabled individuals make choices about the locus of their care, how it is reimbursed, and how they may live quality, independent lives.

Thank you very much.

Senator Dodd. As I say, I am not surprised in some ways that we have not dealt with this problem in the past. And I will ask you all to comment or jump in on this.

The reason I think we have not, in the past, is that, obviously, we have got a population that is living a lot longer than it was in the past.

Also, we have had, over the years, the extended family which was more in place, I guess, than it is today so that people were taking more care of their parents than they have been in more recent years.

And I think most understand that we are not talking about preventing people from going into nursing care facilities; in many instances, that is necessary.

But, really, I think we are talking about forestalling it for as long as possible so that people can live more productive lives.

We heard from one woman here this morning, and Dr. Ostfeld has certainly given us some very worthwhile statistics from the New Haven area about how people are living in this area.

When we talk about partnerships and coordination, we have a tendency, those of us who are the, quote, "professionals" in this area, to talk about Federal Government, about State government, about local government. We talk about the private sector.

I find myself, from time to time, though rarely, including the client when talking about the partnership. And I am wondering how worthwhile it is, beyond this survey issue, to actually draw from people like the Mrs. Kellys.

How do we reach out to that element in the partnership often enough, and how valuable is it to really have that source of information?

Any one of you may want to comment on that.

Commissioner KLINCK. I think the testimony from Joan Quinn on the Promotion of Independent Living Program, in particular, where we are supplying home care, there are so many partnerships, and the client is in that partnership.

They are paying on a sliding fee scale. So, depending upon what your income is, you are actually contributing to your home care.

And I think that you are right; I do not think we can ignore the client because I think that we are talking about the public, the private, the Federal, the State.

I think that you would get acceptance from the client if they are capable of contributing some.

I think the problem here is people are saying, "I cannot afford to pay for my total care. I am willing to pay for a portion of it."

It has been proven in our program, and I am sure in other programs in other States.

So, I think this is something we do have to look into when we are talking about a package.

And when you are talking about an insurance package, a long-term care insurance package, which has been mentioned here today several times, which I think is extremely important for our State and every State to come to grips with, I think it is marketable.

But I think, in that package, you can bring the client in; the company pays a certain portion, and the client pays a certain portion, almost like a deductible.

But I think that we have to include the client, and I think that would be the only way we will be able to produce a good package because no one is going to want to do it all; the Federal Government is not going to do it all; the State is not going to do it all; insurance is not going to do it all.

But I think if we all contribute to this problem and the client is willing to pay a portion, according to what one can afford, it will work.

Senator **Dodd**. I would not say it is whether they want to or not; "cannot" would be more realistic.

I think, too often, those of us who sit in the chairs that I do, elected officials—because we are so supersensitive to the voting constituencies—we have a tendency, I think, to overpromise and raise expectation levels about what State government is going to do, what local government is going to do, what the Federal Government is going to do.

And I think, as a result of that, we do not honestly confront the problems and invite the various elements to participate to the fullest extent possible.

Dr. **Ostfeld**. Senator, I just wanted to say that the information we provided this morning is about one-half of 1 percent of the information we have.

And as it becomes available, we would be delighted to provide it.

We promised the older people in New Haven, who are the sources of our information, that this would not gather dust on the library shelves, but would be made available.

If you deal with people at the level of individuals, as you have suggested, one problem comes up consistently.

Although we can all point to individual exceptions, in the main, older women will care for older men, but older men will not care for older women. That is a problem that we have all got to deal with.

Maybe we need to train the men in different kinds of skills.

And I think this is true of today's older generation males; it may not be true of tomorrow's. But it is a real problem.

Senator **Dodd**. I will come back to that because I think there are some changes.

I see my brother do things with his son, who is 4 years old, that my father did not do with us. Not that my brother loves his children more or less, but it is just the men in my generation are assuming a far greater role in child rearing. And there may be a change in attitudes that we are seeing.

Does anybody else want to comment on that general question?

I think we all agree, but I was wondering if you had anything special to say.

Ms. **Wasik**. The Commission on Long-Term Care is an umbrella policy body and, from a policy perspective, we just have to be very careful that our policies are dealing with data that is collected from the individuals, so that we have the correct information and we are not going on in a blind way.

I agree that we need to stay very close to the frontline and talk to the individuals and work with the doctors who do the research, such as Dr. Ostfeld, next to me.

Ms. **Daubert**. Senator Dodd, when you mentioned the partnership, which is absolutely essential, that, many times, happens automatically.

It is a much different environment of providing care in a home where the health care worker is automatically the guest, versus an institution level, either a nursing home or an acute care hospital.

So, from the very onset, the development of a partnership has to exist because the roles are reversed; the health care worker is the guest, not the patient who is the guest in the institution.

Another point that I would like to make is the recommendation I spoke to in relation to volunteer groups; not only to act as advocates and informational resources, but also to volunteer some time.

I think we have a wealth of people out there who would very gladly give a couple of hours a week for respite care to help Mrs. Kelly and other people or to do some shopping for them while they are doing their shopping.

There are all kinds of senior citizens groups. We have all kinds of social and religious organizations that I do not believe we have begun to tap in any kind of coordinated manner.

Senator DODD. Maybe today we can get some of that out in the State of Connecticut.

Any comment?

Ms. QUINN. Just to pick up on Betty's comment about volunteers, I think that is possible.

The Department on Aging recently received a grant to train volunteers to give respite to Alzheimer's victims and their families.

CCCI did the training for that program, as well as linking of the clients and the volunteers. And it worked very well.

It is hard work. With the Alzheimer's diagnosis, it is very difficult to try and volunteer because, sometimes, volunteers fear the Alzheimer victim.

Another statement heard often is that children should care for their older parents and relatives.

It is not unusual anymore to have an 85-year-old family member with a 65-year-old child where there is role reversal in terms of care; the 85-year-old is the primary caregiver for the 65-year-old.

So, we have to be careful when we say that families should be given the majority of care, although 70 to 80 percent already do.

We have to give some thought to the fact that many of the family members are older, as well, the primary caregivers.

Senator DODD. That is a good point. Let me ask some specific questions, if I can. And I will try to be relatively brief.

And if I do not get to all of them, I may just submit some to you, and you can respond in writing. We have gotten so many questions from the audience.

First of all, Mary Ellen, in the Older Americans Act—I do not want to let this kind of an opportunity go by without asking you to comment on where you think there might be some specific changes that we might make with that act as it affects the whole issue of long-term care.

Commissioner KLINCK. Well, the Older Americans Act, which gives us the responsibility of caring for older Americans, over 60—and we get a good deal of funding from the Federal Government, which we give to the area agencies for administering of grants—my feeling—of course, is everything comes down to finances.

But when we are talking about the grants that are being requested and what we can actually give for home care, particularly when we are trying to take care of the total person when we divide that grant money into different programs, the money that we are actually distributing for home care is very little.

There is a great deal of money distributed for nutrition, which is also vitally important, as was pointed out, because so many people, older people especially, will be diagnosed for some disease and it turns out that they just have not had a good nutritious meal for the past 6 months.

So, nutrition, of course, is where we spend most of our money. I know in this particular time of limited resources this is not the time to say this, but we just do not have enough funds to distribute around the State to give those support services that are needed.

The other thing—when we talk about a program, which was a great program, a 1 year respite care program, where we trained volunteers to care for Alzheimer's victims. I was surprised that we did recruit almost 100 volunteers. We train them and then place them where needed.

The problem is that Federal funding ends this year. Then, what do you do with those trained volunteers?

If we cannot take over that project with State funds, it is lost. There must be a way to judge a good program, where you spend all of that time training people and go back to the Federal Government, and maybe have them look it over to see if it worked, then continue funding, not just to rely on the State to continue funding.

Currently, if the State does not take it over, then there is no alternative.

Through the Older Americans Act the funding that we get is distributed around the State by a formula, and we do have to divide it into so many different categories.

Unfortunately, long-term care is not getting as much money as it should.

Senator DODD. The area agency on aging, I presume, as well, you could be talking about—are there any restrictions in terms of what the area agency on aging can do with regard to long-term care?

Are you restrained under that act from going into some of these services that Mrs. Kelly talked about or others talked about in terms of needs, from a regulatory standpoint?

Commissioner KLINCK. In the State of Connecticut, the area agencies are planning and funding agencies.

Each State, actually, could go further; you could have them be direct service providers, depending upon how it works in your State. We do not see any restrictions there.

Some State area agencies are direct providers; they do use some of the funding for themselves in the field of home care.

In our particular State, they grant the funds out, and we have decided that that is a better way because they are not competing for funds with their grantees.

There are many grantees in the State that are looking for funding.

If area agencies were able to do direct providing themselves, they would be actually competing for the funds that they are granting out.

So, we chose to do it the other way in the State of Connecticut.

Senator DODD. The Older Americans Act also requires that each State have the ombudsman program that you talked about.

Assume, for a second, that we are able to really begin to do some things in the area of long-term care at home, community-based facilities.

What would need to be done? Because the ombudsman program is, by and large, focused on nursing home care, abuses and the like that may occur.

But, obviously, as you get more into long-term care, home and community based, there is a danger, as well, that those community-based services are not going to be adequately run, properly run, that people are getting the proper attention.

What thoughts have you given at all to expanding the program, the ombudsman program, to be able to move into that area?

Commissioner KLINCK. Well, Senator, we are very fortunate in Connecticut because our ombudsman program does extend into the community.

In fact, they are spending probably more time in the community now than they are in nursing homes.

We have patient advocates that are volunteers that we try to recruit to go into the nursing homes.

The ombudsman—right now, we have seven ombudsmen in the State of Connecticut, and they are located in every region in the State.

And they do investigate complaints in the community. Last year, we investigated about 2,000 complaints in the communities.

So, they are looking in that area. What happens when they go into the community, a typical case would be an 82-year-old woman who is just neglecting herself, self-neglect; she does not even realize that she is neglecting herself.

She is living alone. Her house is absolutely a complete disaster. She has not eaten a good meal in maybe 2 or 3 weeks, and maybe she has not even gotten out of bed.

An ombusdman will go in and investigate that complaint, and then try to provide the services.

So, they know what services are available within the community.

If they need real protective services, then we do refer them to the department of human resources, who then takes over the case for a period of time.

But we have done that in Connecticut and have been doing it. And, actually, we have been expanding it every single year.

This year, we will be adding another ombudsman because as we publicize the program, we are getting more and more calls to investigate abused or neglected people.

Family members, because they do not have that needed respite care, are taking care of an older person and are sometimes old, themselves. And if they have, say, Alzheimer's disease, it becomes very frustrating, because the client's actual whole personality changes.

So, out of true frustration, family members, caretakers are actually abusing that person, striking that person. It is not that they mean to; they love them very much.

But from pure exhaustion, because caretakers are not getting the respite care that they need to get out of the home or the opportunity to take that person, say, to an adult day care center for the day, because the funds are not there and that particular type of care is not covered by anything.

It is a big insurance problem in covering Alzheimer patients because they really do not need skilled nursing care, so they are not covered.

But, basically, they should be covered because this is going to be a major problem in this State if we do not think about that.

But we are fortunate that we have a program that is in force now.

Senator Dodd. Well, you know commissioners on aging around the country.

Are we unique in that regard?

Commissioner Klinck. Yes; we are unique in that regard. The Federal funding started with nursing home ombudsmen, and they gave just a small amount of money for that; maybe, like, $50,000, which takes care of one ombudsman office and staff.

Then, most of the States have all volunteers that go into nursing homes, and most States do not have the community program.

We were one of the first in the country to have a community program for ombudsmen, and other States now are getting into it.

In fact, Massachusetts just started the community program about a year ago.

So, we are unique.

Senator Dodd. That is the kind of thing, if you could have someone draft up just a short memo on how this thing is—how it got underway and how it works.

[Subsequent to the hearing, the following was submitted for the record:]

PROTECTIVE SERVICES FOR THE ELDERLY: CONNECTICUT'S EXPERIENCE

In July 1977, Connecticut passed two significant pieces of legislation. The first established a Nursing Home Ombudsman Office in the Department on Aging. The second established a reporting law for protection of the elderly. Both acts were innovations in the United States and have proved to be important adjuncts to the other responsibilities of Connecticut's Department on Aging.

The Ombudsman Office

The Ombudsman Office consists of a State Ombudsman and Regional Ombudsmen who are located in offices throughout the State. The Ombudsman Office is responsible for receiving and investigating complaints concerning residents of chronic and convalescent nursing homes (SNFs), rest homes with nursing supervision (ICFs), and homes for the aged (HAs). In addition, the Ombudsmen are responsible for investigating reports made to them of abuse, neglect, abandonment and exploitation of any person 60 years or older in the State. After reports are made to them, they must investigate promptly.

Also operating out of the Ombudsman Office is the State Conservator Program. State Conservators act on behalf of the Commissioner on Aging. The Commissioner on Aging is appointed conservator only in those situations where no other suitable person is available to serve and where the client is at least 60 years of age and has no more than $1,500 in liquid assets. The Conservator may be appointed as conservator of person, estate, or both, or as temporary conservator, which appointment is good for only 30 days.

The Ombudsman Office also has a Volunteer Patient Advocate Program. The Ombudsmen, along with the Chief of Volunteer Services, recruit and train volunteers to work in nursing homes. After a two-day training, the volunteer advocates are assigned to one or more homes that they must visit at least once a week. Any problem found is brought to the attention of the administrator where, hopefully, it is resolved. Confidentiality is maintained concerning complainants' and complainee's names. The advocates attend follow-up training sessions to keep abreast of new regulations and policies concerning nursing homes.

HOW ELDERLY PROTECTIVE SERVICES WORK

Under Connecticut's elderly protective services law, the State Departments on Aging and Human Resources work together to provide help to persons 60 years or older who are victims of abuse, neglect, abandonment or exploitation.

A wide range of professionals and paraprofessionals, whose work brings them into contact with the elderly, are mandated to report cases of abuse and neglect to the State Ombudsman or one of the Regional Ombudsmen within five calendar days of the time the abuse is discovered. Failure to report such a situation may result in a fine of not more than $500. Legal immunity from any civil or criminal liability related to a mandatory report is provided to those who report in good faith, except for cases of perjury. There are a number of provisions tailored to protect the rights of elderly persons who may need protective services. Two important ones are as follows:

1. Elderly persons must give their consent before services are arranged for them.
2. If it is felt that an elderly person lacks the capacity to give consent for state intervention, a petition for custody of the person may be filed in probate court. The elderly person must be represented by an attorney during those proceedings.

A temporary conservator may be appointed by the appropriate probate judge if there is a certificate signed by two physicians, licensed to practice medicine in Connecticut, stating that they have examined the client and found her/him to be incapable and that irreparable injury to the mental or physical health or financial or legal affairs of the respondent will result if no conservator is appointed immediately. A temporary conservatorship is valid for no more than 30 days.

The Regional Ombudsman responsible for the town in which the abuse occurs must make an immediate investigation of the situation. The Ombudsman obtains all available information from the client, family, friends, and referrant after which s(he) determines whether the case is valid. If the situation meets the appropriate criteria, the Ombudsman refers her/his assessment of the client and recommendations for action to the closest district office of the Department of Human Resources. The protective services worker then visits the client and arranges for the provision of necessary services that will alleviate the problems. The effort is, always, to keep the client in his home rather than to institutionalize.

The Ombudsman Office maintains a statewide file on all clients and receives 10-day, 45-day and subsequent 90-day reports on each individual case from the protective services worker. There are six district offices of Human Resources, each housing an elderly protective services unit consisting of a supervisor and at least one worker.

With the initiation of the protective services program, all mandatory reporters were sent a flyer informing them of their responsibility under the law as well as the names of the Regional Ombudsmen and the towns in their regions. Mandatory report forms were included in the mailing. The Department on Aging and the Department of Human Resources have and continue to hold inservices for agencies throughout the state to discuss the program more fully with those persons who are involved.

TYPES OF ABUSE

It is not known whether elderly abuse is a relatively new phenomenon or whether it previously has simply been unrecognized. The extended family of the past offered many opportunities for abuse, inasmuch as three, sometimes four, generations lived under the same roof. Life-styles were different from those of today, however, in that the majority of grown children, when married, settled down in the same town in which they and their spouses had been reared. This provided much needed support for aging parents and relatives. The majority of women did not work outside the home which meant that help was always available either in the same housefold where the elders lived or close by.

Today, society is entirely different. Young people are extremely mobile, often ending up far from family and friends. Living accommodations are no longer large rambling dwellings,capable of housing more than one family, but rather efficiency apartments, condominiums or houses, barely large enough for a small family. Many wifes and mothers work full-time, thus prohibiting an older, dependent parent from moving in and being cared for unless outside help is brought in. Finally, the population is living longer, bringing along increased physical and mental infirmities.

Connecticut's law delineates four categories of abuse which are reportable to the Ombudsman Office. Following are the definitions of those four categories:

1. Abuse Abuse includes but is not limited to the willful infliction of physical pain, injury or mental anguish or the willful deprivation, by a caretaker, of services which are necessary to maintain physical and mental health.

2. Neglect Neglect refers to an elderly person who is either living alone and not capable of providing for him/herself services necessary to maintain physical and mental health or is not receiving necessary services from the responsible caretaker.

3. Abandonment Abandonment refers to the desertion or willful forsaking of an aged person by a caretaker or the forgoing of duties and obligations owed an elderly person by a caretaker or other person.

4. Exploitation Exploitation refers to the act or process of taking advantage of an elderly person by another person or caretaker whether for monetary, personal, or other benefits, or gain or profit.

PROGRAM EXPERIENCE

Many facts have emerged from the Ombudsman experience that play a key role in abuse, neglect, abandonment, and exploitation of the elderly.

1. Abuse, of the four types mentioned, occurs in rural, suburban and urban settings.
2. Abuse occurs in all economic groups.
3. The majority of (abused) clients are women.
4. The majority of clients are 80 years or older.
5. The majority of abusers are family members.
6. Advanced age, alcoholism, and psychiatric problems appear to influence the family member's handling of an older person.

As of June, 1986, the Ombudsman Office has investigated more than 12,000 cases of abuse, neglect, abandonment and exploitation of the elderly. By far the largest number of cases have involved neglect, either by self or by the caretaker. The caretaker is, most frequently, a family members, either a grown child or spouse.

According to the State Ombudsman's statistics, the greatest number of cases involve clients from urban areas, the smallest number are from rural areas, and the remainder from suburban areas. These percentages do not correspond with the actual percentages of elderly persons living in those areas. The greatest number of elderly, in Connecticut, live in suburban areas, the next largest in urban, and the smallest percentage in rural areas. The discrepancies may be due to two factors: (1) some towns may not be reporting cases or may not know about the program; and (2) those elderly living in urban areas may be experiencing more problems than those residents of suburban areas. Although the largest number of cases involve clients in the lower socioeconomic groups, many reports are received of abuse, neglect and exploitation of elderly in the middle and upper-middle class.

That the majority of clients are women is no surprise, especially when this statistic is coupled with the fact that the largest proportion of clients are 80 years or older. Women live longer than men and, therefore, problems become more severe as women become older and more fragile.

A great many older citizens reside with a family member. Therefore, again, it comes as no surprise to discover that most neglectful caretakers are family members. It is important to remember, however, that many cases involve self-neglect, where older people have simply reached a point, both mentally and physically, when they are no longer capable and do not realize that they are neglecting themselves. Age, alcoholism and psychiatric problems must be considered when assessing the abusing caretaker.

It is not unusual to find a 65- to 70-year-old son or daughter attempting to care for an 85- to 90-year-old parent. On many instances, the 65-year-old caretaker cannot manage his/her own needs and is, therefore, frustrated over having to carry the additional burden of an elderly parent. Frequently, this frustration results in physical acting out against the older person. In many instances where abuse is present, as soon as the burden or responsibility is removed from the caretaker (abuser) and ancillary services are introduced, the abuse and neglect stop. The caretaker simply needs relief from the pressure of providing continuous, uninterrupted care.

It is felt, however, that many caretakers abuse, neglect, and exploit older persons for other reasons such as money, property or assets. Deprivation of food, verbal abuse, and physical beating and threats are weapons used to force an older person to sign over property, bankbooks, or social security checks. Many times the Ombudsmen have discovered elderly clients, suffering from senile dementia, who have unknowingly signed away their homes or property to a relative. In some instances, a younger relative may ask the older person to change his/her bank account to a joint one, alleging that it would be easier for him to sign checks and purchase goods. Once accomplished, the relative closes out the account and leaves the state.

CASE RESOLUTION AND MONITORING OF CLIENTS

The reporting of protective services clients and the investigation carried out by the Ombudsmen are only part of the program's requirements. Another important aspect deals with the arrangement of services and monitoring of the client's progress by the protective services worker. Many services are used by the protective services worker: homemakers; home health aides; visiting nurses; physicians; ambulance; hospitalization; meals on wheels; chore service; friendly visitors; companions; counseling on alcohol, mental health and family problems; conservatorships; and police intervention. In more severe cases, admission to a nursing home or commitment to a mental hospital may be needed.

In cases where a client refuses assistance and where the Ombudsman has judged the client to be incapable of making such a decision, the case is referred anyway. The protective services worker then obtains a psychiatric evaluation in those cases in which the client is deemed to be a danger to him/herself or others.

CONCLUSION

Connecticut is proud of its innovative law dealing with the abused elderly. It is believed that such programs are needed throughout the country. Whether or not elderly abuse is on the upswing is a guess, but judging from Connecticut's eight-year experience, many older people are living in drastic situations that require intervention for their survival.

July 31, 1986

Written by Jacque Walker
State Ombudsman
Connecticut

Senator DODD. If nothing else comes out of hearings like this, we may convince some more people in the Senate to go back to their own States with this kind of thing.

Commissioner KLINCK. What I could share with you is our State legislation because it was drafted through Connecticut State legislation. I will share that with you.

[Subsequent to the hearing, the following was received from Commissioner Klinck for the record:]

Connecticut Statutes

CHAPTER 303

DEPARTMENT ON AGING

Sec. 17-135a. Nursing home ombudsmen office. Appointment of state ombudsman and regional ombudsmen. Removal. There is established a nursing home ombudsmen office within the state department on aging which shall be responsible for receiving and resolving health and human services complaints affecting patients or residents in nursing home facilities as defined in section 19a-521. The commissioner on aging shall appoint a state ombudsman and assistant regional ombudsmen, each of whom shall serve for terms coterminous with the term of the governor or until successors are chosen, whichever is later. Such ombudsmen may not be removed, except for cause, which shall include, but not be limited to, misconduct, material neglect of duty or incompetence in the conduct of the office. Such state ombudsman and the regional ombudsmen shall appoint local volunteer patients' advocates, as provided in section 17-135b, to carry out the provisions of sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554.

(P.A. 77-575, S. 1, 23; P.A. 81-167.)

History: P.A. 81-167 changed the number of assistant regional ombudsmen the commissioner on aging may appoint from a maximum of five to a number to be determined by the commissioner and deleted obsolete provisions re original appointment dates and terms.

See title 2c re termination under "Sunset Law."
See chapter 814 re protection of the elderly.

Sec. 17-135b. Patients' advocates. Appointment, expenses, removal. Use of trained volunteers. (a) Patients' advocates shall be appointed by the state ombudsman, in consultation with the regional ombudsmen, for each region in sufficient number to serve the nursing home facilities within such region. Such patients' advocates shall, if possible, be residents of the region in which they will serve, and shall have demonstrated an interest in the care of the elderly. Patients' advocates shall serve without compensation but may be reimbursed for reasonable expenses incurred in the performance of their duties, within available appropriations.

(b) The patients' advocates shall be appointed from among nominees submitted by the chief administrative officer and the committee on aging, if any, for each town, the area agency on aging and the director of health serving each town.

Sec. 17-135e. Supervision of state ombudsman. Investigative power. (a) The state ombudsman shall be under the direct supervision of and accountable to the commissioner on aging.

(b) The state ombudsman is authorized to investigate and make reports and recommendations concerning any act or the failure to act by any agency, official or public employee, with respect to their responsibilities and duties in connection with nursing home facilities, except the courts and their personnel, legislative bodies and their personnel and the chief executive of the state and his personal staff and all elected officials.

(P.A. 77-575, S. 5, 23.)

Sec. 17-135f. Duties of regional ombudsmen. The five regional ombudsmen shall: (1) Be responsible for the patients' advocates in the performance of their duties and shall assist such advocates in resolving problems; (2) investigate problems and complaints brought to them by such advocates and shall direct any complaint, so investigated, to the state ombudsman for further action, if necessary; (3) collect data from their regions which shall be directed to the state ombudsman for research and analysis; (4) carry out policies and procedures in their regions as established by the nursing home ombudsmen office, including reporting in writing any action taken concerning a complaint; (5) collaborate with local and regional officials and organizations in attempting to clarify and resolve complaints and (6) establish local liaison and working relationships with the media, speakers bureaus and civic organizations and develop an ongoing program of publicizing the ombudsmen office, its purposes and mode of operation.

(P.A. 77-575, S. 6, 23.)

See chapter 814 re protection of the elderly

Sec. 17-135g. (Formerly Sec. 19-621). Duties of patients' advocates. Posting by nursing home facilities. Funding. (a) Patients' advocates, under supervision of the regional ombudsmen, shall assist the regional ombudsmen in the performance of all duties and responsibilities including, but not limited to, the following: (1) The establishment of program policies and procedures for receiving, evaluating, referring and resolving complaints from nursing home facility patients and families, employees of nursing home facilities and the general public, relating to nursing home facilities; (2) the carrying out of established policies and procedures, including receipt of appropriate complaints and the reporting in writing on any action taken; (3) the collaboration with state officials and other appropriate organizations to clarify complaints and the pursuit of all necessary steps to resolve such complaints; (4) the provision of information as requested to state agencies and organizations; (5) the collection of data for research and analysis to substantiate recommendations for policy and program changes and the study of the problems encountered therein; (6) the identification and documentation of significant problems affecting a large segment of the nursing home facility population and the communication of the documented problem area to groups or agencies with similar concerns and jurisdictional authority to deal with such problems; (7) the establishment of local liaison and working relationships with the media, speakers bureaus and civic organizations and the development of an ongoing program of publicizing the role of the state ombudsmen office and the patients' advocates; (8) the submission of legislative recommendations to the general assembly; (9) the facilitation of private legal action for patients if necessary; (10) assuring that the patients' bill of rights, as established in section 19a-550, is properly posted and is distributed to each patient or, if such patient is a minor or incompetent, to his relative, guardian, conservator or sponsoring agency and assuring that all elements and provisions of the patients' bill of rights are adhered to properly; (11) assuring that all mandated posting of the availability of reports has been complied with; and (12) aiding patients in administrative procedures relating to transfers and discharges, and aiding in insuring that patients are satisfied with the management of their financial affairs.

(b) Such patients' advocates shall report to the commissioner on aging, the commissioner of health services and to the local director of health, board of health or official charged with the enforcement of the health laws any violations of subsection (a) of this section.

(c) All nursing home facilities shall post or cause to be posted in a conspicuous place therein a list of the names of the appropriate patients' advocates and the names, addresses, and telephone numbers of the appropriate ombudsmen.

(d) The commissioner on aging shall have authority to seek funding for the purposes contained in this section from public and private sources, including but not limited to any federal or state funded programs.

(P.A. 75-468, S. 11, 17; P.A. 76-331, S. 14, 16; P.A. 77-575, S. 14, 23; 77-604, S. 18, 84; 77-614, S. 323, 610.)

History: P.A. 76-331 rewrote provisions re patients' advocates in Subsec. (a), required posting of availability of reports rather than reports themselves in Subdiv. (2) of Subsec. (b), rephrased Subdiv. (3) and added Subdivs. (5) and (6) re financial affairs and well-being of patients and added Subsec. (e) re funding sources; P.A. 77-575 deleted former Subsecs. (a) and (b) re qualifications, appointment and duties of advocates, inserted new Subsec. (a) placing advocates under ombudsmen and listing duties, relettering remaining Subsecs. accordingly, required reports to commissioner of health and required names, addresses and telephone numbers of ombudsmen but names only of advocates; P.A. 77-604 rephrased Subdiv. (4) of Subsec. (b); P.A. 77-614 replaced commissioner of health with commissioner of health services, effective January 1, 1979; Sec. 19-621 transferred to Sec. 17-135g in 1979.

Sec. 17-135h. Duty to report suspected abuse, neglect, exploitation or abandonment. Penalty. Confidentiality. Immunity. Notice to complainant. Registry. (a) On and after July 12, 1977, any physician or surgeon registered under the provisions of chapter 370 or 371, any resident physician or intern in any hospital in this state, whether or not so registered, and any registered nurse, licensed practical nurse, medical examiner, dentist, osteopath, optometrist, chiropractor, podiatrist, social worker, clergyman, police officer, pharmacist, physical therapist, nursing home facility administrator, nurses aide or orderly in a nursing home facility, any person paid for caring for a patient in a nursing home facility, any staff person employed by a nursing home facility and any regional ombudsman or patients' advocate who has reasonable cause to suspect or believe that a patient in a nursing home facility has been abused, neglected, exploited or abandoned, or is in a condition which is the result of such abuse, neglect, exploitation or abandonment, shall within five calendar days report such information or cause a report to be made in any reasonable manner to the nursing home ombudsmen office. Any person required to report under the provision of this section who fails to make such report within the prescribed time period shall be fined not more than five hundred dollars.

(b) Such report shall contain the name and address of the nursing home facility, the name of the involved patient, information regarding the nature and extent of the abuse, neglect, exploitation or abandonment and any other information which the reporter believes might be helpful in an investigation of the case and for the protection of the patient.

(c) Any other person having reasonable cause to believe that a patient in a nursing home facility is being, or has been, abused, neglected, exploited or abandoned, or any person who wishes to file any other complaint regarding a nursing home facility, shall report such information in accordance with subsection (b) in any reasonable manner to the nursing home ombudsmen office.

(d) Such report or complaint shall not be deemed a public record, and shall not be subject to the provisions of section 1-19. Information derived from such reports or complaints for which reasonable grounds are determined to exist after investigation as provided for in section 17-135i, including the identity of the nursing home, the number of complaints received, the number of complaints substantiated and the types of complaints, may be disclosed by the state ombudsman, except that in no case shall the name of the patient or the complainant be revealed, unless such person specifically requests such disclosure or unless a judicial proceeding results from such report or complaint.

17-135
(d)

(e) Anyone who makes a report or complaint pursuant to this section or who testifies in any administrative or judicial proceeding arising from the report shall be immune from any civil or criminal liability on account of such report or complaint or testimony, except for liability for perjury, unless such person acted in bad faith or with malicious purpose.

(f) The person filing a report or complaint pursuant to the provisions of this section shall be notified of the findings of any investigation conducted by the nursing home ombudsmen office, upon request.

(g) The state ombudsman shall maintain a registry of the reports received, the investigations made, the findings and the actions recommended and taken.

(P.A. 77-575, S. 7, 23; P.A. 80-190, S. 5; 80-433.)

History: P.A. 80-190 deleted reference to coroners in Subsec. (a); P.A. 80-433 expanded disclosure provisions in Subsec. (d).

See Sec. 46a-15.

Sec. 17-135i. Review of report or complaint. Investigation. Referral to commissioner of health services or other action. Notice to complainant. Upon receipt of a report or complaint as provided in section 17-135h, the ombudsmen shall determine immediately whether there are reasonable grounds for an investigation. If it is determined that reasonable grounds do not exist for an investigation, the complainant or the person making the report shall be notified of this determination within five working days after the receipt of such complaint or report. If such reasonable grounds are found, the appropriate regional ombudsman in conjunction with the patients' advocates, shall investigate such report or complaint within ten working days thereafter. The regional ombudsman shall complete his investigation and make a report of his findings, within fifteen working days after the receipt of the complaint or report, a copy of which shall be sent to the state ombudsman. If the investigation indicates that there is a possible violation of the provisions of the public health code with respect to licensing requirements, the regional ombudsman shall refer the report or complaint, together with a report of his investigation, to the commissioner of health services for appropriate action under the provisions of sections 19a-523 to 19a-529, inclusive, and 19a-531 to 19a-540, inclusive. If no violation of the public health code is indicated, the regional ombudsman shall take whatever action he deems necessary, and shall notify the complainant or the person making the report, of the action taken within fifteen working days after receipt of the complaint or report.

(P.A. 77-575, S. 8, 23, 77-614, S. 323, 587, 610, P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 replaced commissioner of health with commissioner of health services, effective January 1, 1979.

Sec. 17-135j. Civil immunity of state employees. Representation by attorney general. Neither the state ombudsman, nor any employee of the nursing home ombudsmen office, nor the regional ombudsmen, patients' advocates or any employee of any other state agency shall be held personally liable in any civil action for damages on account of any act or omission not wanton or wilful in the performance of his responsibilities or duties under sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554. Any person to whom the provisions of this section apply and against whom any action is brought on account of any alleged act or omission shall be represented therein by the attorney general in the manner provided in chapter 35.

(P.A. 77-575, S. 16, 23.)

Sec. 17-135k. Penalty for failure to cooperate with ombudsman or patients' advocate. Access to public records. Confidentiality. Acceptance of assistance. (a) Any nursing home facility which refuses to permit the state ombudsman or any regional ombudsman or any patients' advocate entry into such facility or refuses to cooperate with the state ombudsman, or any regional ombudsman or any patients' advocate in the carrying out of their mandated duties and responsibilities enumerated under sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554 or refuses to permit patients or staff to communicate freely with the state ombudsman or any regional ombudsman or any patients' advocate shall be subject to the penalty prescribed for a class D violation under section 19a-527.

(b) In carrying out the duties enumerated in sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554, the state ombudsman, the regional ombudsmen and the patients' advocates shall have access to all relevant public records, except that records which are confidential to a patient shall only be divulged with the written consent of the patient.

(c) In the performance of the duties and responsibilities enumerated under sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554, the state ombudsman, the regional ombudsmen and the patients' advocates may utilize any other state department, agency or commission, or any other public or private agencies, groups or individuals who are appropriate and who may be available.

(P.A. 77-575, S. 17, 23.)

Sec. 17-135l. Regulations. Regulations shall be promulgated by the commissioner on aging to carry out the provisions of sections 17-135a to 17-135m, inclusive, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532 and 19a-554.

(P.A. 77-575, S. 19, 23.)

Sec. 17-135m. Annual report. On or before September 1, 1978, and annually thereafter, the state ombudsman shall submit, through the commissioner on aging, a report to the governor and the general assembly of the activities of the ombudsmen office during the prior fiscal year and a projected budget for the coming fiscal year. The report shall include, but not be limited to, the number and general pattern of complaints received by the ombudsmen office, the number and nature of administrative acts investigated, the action taken on such investigations, the results of such actions and any opinions or recommendations which will further the state's capabilities in resolving nursing home complaints.

(P.A. 77-575, S. 18, 23; P.A. 78-331, S. 31, 58.)

[illegible] acts investigated in addition to the number of acts

Connecticut Statutes

CHAPTER 814*

PROTECTION OF THE ELDERLY

Sec. 46a-14. Definitions. For purposes of this chapter:

(1) The term "elderly person" means any resident of Connecticut who is sixty years of age or older.

(2) An elderly person shall be deemed to be "in need of protective services" if such person is unable to perform or obtain services which are necessary to maintain physical and mental health.

(3) The term "services which are necessary to maintain physical and mental health" includes, but is not limited to, the provision of medical care for physical and mental health needs, the relocation of an elderly person to a facility or institution able to offer such care, assistance in personal hygiene, food, clothing, adequately heated and ventilated shelter, protection from health and safety hazards, protection from maltreatment the result of which includes, but is not limited to, malnutrition, deprivation of necessities or physical punishment, and transportation necessary to secure any of the above stated needs, except that this term shall not include taking such person into custody without consent except as provided in this chapter.

(4) The term "protective services" means services provided by the state or other governmental or private organizations or individuals which are necessary to prevent abuse, neglect, exploitation or abandonment. Abuse includes, but is not limited to, the wilful infliction of physical pain, injury or mental anguish, or the wilful deprivation by a caretaker of services which are necessary to maintain physical and mental health. Neglect refers to an elderly person who is either living alone and not able to provide for oneself the services which are necessary to maintain physical and mental health or is not receiving the said necessary services from the responsible caretaker. Exploitation refers to the act or process of taking advantage of an elderly person by another person or caretaker whether for monetary, personal or other benefit, gain or profit. Abandonment refers to the desertion or wilful forsaking of an elderly person by a caretaker or the foregoing of duties or the withdrawal or neglect of duties and obligations owed an elderly person by a caretaker or other person.

(5) The term "caretaker" means a person who has the responsibility for the care of an elderly person as a result of family relationship or who has assumed the responsibility for the care of the elderly voluntarily, by contract or by order of a court of competent jurisdiction.

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*See Secs. 2c-2b, 17-135a—17-135m, 19a-523, 19a-524, 19a-530, 19a-531, 19a-532, 19a-554.

(6) "State ombudsman" and "regional ombudsmen" mean the persons appointed by the commissioner on aging under the provisions of section 17-135a.

(P.A. 77-613, S. 1, 15.)

Sec. 46a-15. Report of suspected abuse, neglect, exploitation, abandonment or need for protective services. Penalty for failure to report. Immunity for report or testimony. (a) Any physician or surgeon licensed under the provisions of chapter 370 or 371, any resident physician or intern in any hospital in this state, whether or not so licensed, any registered nurse, any nursing home administrator, nurse's aide or orderly in a nursing home facility, any person paid for caring for a patient in a nursing home facility, any staff person employed by a nursing home facility, any patients' advocate and any licensed practical nurse, medical examiner, dentist, osteopath, optometrist, chiropractor, podiatrist, social worker, clergyman, police officer, pharmacist or physical therapist, who has reasonable cause to suspect or believe that any elderly person has been abused, neglected, exploited or abandoned, or is in a condition which is the result of such abuse, neglect, exploitation or abandonment, or who is in need of protective services, shall within five calendar days report such information or cause a report to be made in any reasonable manner to the commissioner on aging or to the person or persons designated by him to receive such reports. Any person required to report under the provisions of this section who fails to make such report shall be fined not more than five hundred dollars.

(b) Such report shall contain the name and address of the involved elderly person, information regarding the nature and extent of the abuse, neglect, exploitation or abandonment, and any other information which the reporter believes might be helpful in an investigation of the case and the protection of such elderly person.

(c) Any other person having reasonable cause to believe that an elderly person is being, or has been, abused, neglected, exploited or abandoned, or who is in need of protective services may report such information in any reasonable manner to the commissioner or his designee.

(d) Any person who makes any report pursuant to this chapter, or who testifies in any administrative or judicial proceeding arising from such report shall be immune from any civil or criminal liability on account of such report or testimony, except for liability for perjury, unless such person acted in bad faith or with malicious purpose.

(e) For the purposes of sections 46a-14 to 46a-26, inclusive, the treatment of any elderly person by a Christian Science practitioner, in lieu of treatment by a licensed practitioner of the healing arts, shall not of itself constitute grounds for the implementation of protective services.

(P.A. 77-613, S. 2, 15; P.A. 78-30; P.A. 80-190, S. 11; P.A. 84-546, S. 160, 173.)

History: P.A. 78-30 added Subsec. (e) re treatment of elderly person by Christian Science practitioner; P.A. 80-190 removed coroners from list of those required to make report in Subsec. (a); P.A. 84-546 made technical changes, substituting "licensed" for "registered" where appearing.

See Sec. 17-135h.

Sec. 46a-16. Evaluation of report. Findings and recommendation. Registry. Confidentiality. (a) The commissioner upon receiving a report that an elderly person allegedly is being, or has been, abused, neglected, exploited or abandoned, or is in need of protective services shall cause a prompt and thorough evaluation to be made, through the appropriate regional ombudsman, to determine the situation relative to the condition of the elderly person and what action and services, if any, are required. The evaluation shall include a visit to the named elderly person and consultation with those individuals having knowledge of the facts of the particular case. Upon completion of the evaluation of each case, written findings shall be prepared which shall include recommended action and a determination of whether protective services are needed. The person filing the report shall be notified of the findings, upon request.

(b) Each regional ombudsman shall maintain a registry of the reports received, the evaluation and findings and the actions recommended, and shall furnish copies of such data to the department on aging for a statewide registry.

(c) Neither the original report nor the evaluation report of the regional ombudsman shall be deemed a public record or be subject to the provisions of section 1-19. The name of the person making the original report or any person mentioned in such report shall not be disclosed unless the person making the original report specifically requests such disclosure or unless a judicial proceeding results therefrom.

(P.A. 77-613, S. 3, 15.)

Sec. 46a-17. Referral to department of human resources. Injunction against interference by caretaker. (a) If it is determined that an elderly person is in need of protective services, the regional ombudsman shall refer the case to the department of human resources for the provision of necessary services, provided the elderly person consents. If the elderly person fails to consent and the regional ombudsman has reason to believe that such elderly person lacks capacity to consent, the regional ombudsman shall refer the case to the department of human resources for a determination pursuant to section 46a-20 of whether a petition for appointment of a conservator should be filed.

(b) If the caretaker of an elderly person who has consented to the receipt of reasonable and necessary protective services refuses to allow the provision of such services to such elderly person, the commissioner of human resources may petition the superior court or the probate court for an order enjoining the caretaker from interfering with the provision of protective services to the elderly person. The petition shall allege specific facts sufficient to show that the elderly person is in need of protective services and consents to their provision and that the caretaker refuses to allow the provision of such services. If the judge finds that the elderly person is in need of such services and has been prevented by the caretaker from receiving the same, the judge may issue an order enjoining the caretaker from interfering with the provision of protective services to the elderly person.

(P.A. 77-613, S. 4, 15; 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced commissioner and department of social services with commissioner and department of human resources, effective January 1, 1979.

Sec. 46a-18. Access to records. Authority of departments of human resources and aging. Any person, department, agency or commission authorized to carry out the duties enumerated in this chapter shall have access to all relevant records, except that records which are confidential to an elderly person shall only be divulged with the written consent of the elderly person or his representative. The authority of the department of human resources, and the department on aging under this chapter shall include, but not be limited to, the right to initiate or otherwise take those actions necessary to assure the health, safety and welfare of any elderly person, subject to any specific requirement for individual consent, and the right to authorize the transfer of an elderly person from a nursing home.

(P.A. 77-613, S. 5, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced department of social services with department of human resources, effective January 1, 1979.

See Secs. 19a-534, 19a-535.

Sec. 46a-19. Lack of consent or withdrawal of consent. Reports to and comments by ombudsman. (a) If an elderly person does not consent to the receipt of reasonable and necessary protective services, or if such person withdraws the consent, such services shall not be provided or continued, except that if the commissioner of human resources has reason to believe that such elderly person lacks capacity to consent, he may seek court authorization to provide necessary services, as provided in section 46a-20.

(b) The department of human resources, within ten calendar days of the referral of any case for the provision of protective services, shall furnish the regional ombudsman a written report outlining the intended plan of services. The regional ombudsman shall have the right to comment on the proposed plan, and a copy of the regional ombudsman's comments shall be forwarded to the state ombudsman for subsequent action, if required.

(P.A. 77-613, S. 6, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced commissioner and department of social services with commissioner and department of human resources, effective January 1, 1979.

Sec. 46a-20. Appointment of conservator for elderly person lacking capacity to consent to protective services. (a) If the commissioner of human resources finds that an elderly person is being abused, neglected, exploited or abandoned and lacks capacity to consent to reasonable and necessary protective services, he may petition the probate court for appointment of a conservator of the elderly person pursuant to the provisions of chapter 779, in order to obtain such consent.

(b) Such elderly person or the individual, agency or organization designated to be responsible for the personal welfare of the elderly person shall have the right to bring a motion in the cause for review of the probate court's determination regarding the elderly person's capacity or an order issued pursuant to this chapter.

(c) The probate court may appoint, if it deems appropriate, the commissioner of human resources to be the conservator of the person of such elderly person.

(d) In any proceeding in probate court pursuant to provisions of this chapter, the probate court shall appoint an attorney to represent the elderly person if he is without other legal representation.

(P.A. 77-613, S. 7, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced commissioner of social services with commissioner of human resources, effective January 1, 1979.

Sec. 46a-21. Assistance by public or private agencies. In performing the duties set forth in the chapter, the regional ombudsmen and the department of human resources may request the assistance of the staffs and resources of all appropriate state departments, agencies and commissions and local health directors, and may utilize any other public or private agencies, groups or individuals who are appropriate and who may be available.

(P.A. 77-613, S. 8, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced department of social services with department of human resources, effective January 1, 1979.

Sec. 46a-22. Periodic review of cases in which protective services are provided. Consent to continuation of services. Subsequent to the authorization for the provision of reasonable and necessary protective services, the department of human resources shall initiate a review of each case within forty-five days, to determine whether continuation of, or modification in, the services provided is warranted. A decision to continue the provision of such services should be made in concert with appropriate personnel from other involved state and local groups, agencies and departments, and shall comply with the consent provisions of this chapter. Reevaluations of each such case shall be made every ninety days thereafter. The department of human resources shall advise the appropriate regional ombudsman of the decisions relative to continuation of protective services for each such elderly person.

(P.A. 77-613, S. 9, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced department of social services with department of human resources, effective January 1, 1979.

Sec. 46a-23. Payment for protective services. Procedures when elderly person unable to pay. Concurrent with the implementation of any protective services, an evaluation shall be undertaken by the department of human resources, pursuant to regulations which shall be adopted by the commissioner of human resources, in accordance with chapter 54, regarding the elderly person's financial capability for paying for the protective services. If the person is so able, procedures for the reimbursement for the costs of providing the needed protective services shall be initiated. If it is determined that the person is not financially capable of paying for such needed services, the services shall be provided in accordance with policies and procedures established by the commissioner of human resources for the provision of welfare benefits under such circumstances.

(P.A. 77-613, S. 10, 15, 77-614, S. 521, 587, 610; P.A. 78-303, S. 85, 136; P.A. 80-30, S. 1, 2.)

History: P.A. 77-614 and P.A. 78-303 replaced commissioner and department of social services with commissioner and department of human resources, effective January 1, 1979; P.A. 80-30 made minor wording changes and made initiation of procedures for reimbursement of costs mandatory if person is able to pay, substituting "shall" for "should".

Sec. 46a-24. Referral for criminal investigation or proceedings. If as a result of any investigation initiated under the provisions of this chapter, a determination is made that a caretaker or other person has abused, neglected, exploited or abandoned an elderly person, such information shall be referred in writing to the appropriate office of the state's attorney, which shall conduct such further investigation, if any, is deemed necessary and shall determine whether criminal proceedings should be initiated against such caretaker or other person, in accordance with applicable state law.

(P.A. 77-613, S. 11, 15.)

Sec. 46a-25. Regulations. Regulations shall be promulgated by the commissioner on aging, in conjunction with the commissioner of human resources, to carry out the provisions of this chapter.

(P.A. 77-613, S. 12, 15, 77-614, S. 521, 587, 610, P.A. 78-303, S. 85, 136.)

History: P.A. 77-614 and P.A. 78-303 replaced commissioner of social services with commissioner of human resources, effective January 1, 1979.

Sec. 46a-26. Reimbursement of certain funds expended for purposes of chapter. Section 46a-26 is repealed.

(P.A. 77-613, S. 13, 15; 77-614, S. 521, 587, 610, P.A. 78-265, S. 2, 3, 78-303, S. 85, 136.)

Secs. 46a-27 to 46a-50. Reserved for future use.

Note: Chapters 814a and 814b are also reserved for future use.

Senator DODD. Doctor, again, we thank you for coming. First, all the statistics, I think, sometimes can be dizzying, trying to keep the numbers all straight.

How reflective do you believe that the New Haven survey is of national data?

Have you seen national data that would tend to confirm what you have discovered in this particular community?

Are we the exception, with less of a problem in terms of these areas, or more?

Dr. OSTFELD. Senator, I think that, when we present it, it will be fairly representative of all States which are not primarily rural.

I have good reason to believe that. In parallel with the study that we are doing in New Haven, there is another study with almost the same kind of methods in Boston with findings that are almost superimposable.

Most older people in the United States live in central cities in the Midwest and Northeast. That is still true.

Our picture of most older Americans living in the Sun Belt is not true. Older people are the least mobile segment of our society.

So, I believe that, for most highly industrialized States, what we find in New Haven is representative of those areas.

Senator DODD. We hear that data, and we have heard a lot of comment this morning about what sorts of services ought to be made available.

We heard about the respite care, obviously, over and over again.

Would you care to expand that list or contract it in any way, as we talk about a time of limited resources?

Dr. OSTFELD. Well, I think, the general, I would agree with what Betty Daubert said or implied—and I hope I am getting you correctly, Betty—that a large proportion of the help can come from well-intentioned, well-motivated people who are willing to put their minds to learning relatively few skills.

In taking care of the elderly, it is more important to know the disability than it is to know the diagnosis. And humanity precedes technology in helping older people.

There is one other thing that I would like to see happen.

Most older people are taking 3, 4, 5, 10, 15 medications; many of them have been taken for years; others have been recently added; some are over the counter; some are by prescription.

It is difficult to tell which ones you should still be taking and which ones you should throw away.

I have not infrequently seen older people taking two medications with directly opposing effects.

And I would like to see some way to get the medicine chests of older people cleaned out.

Senator DODD. That is the kind of medical thing—I presume we have medically-trained people, not necessarily physicians, but certainly registered nurses or the like who could come in for a day in some of these places and just go from apartment to apartment and be able to give people some advice on some things.

Dr. OSTFELD. You do not need all kinds of special scientific expertise to do these things.

Mostly, you need humanity and willingness to learn a little bit.

Senator DODD. There are so many questions for all of you, but I am afraid I am already taking more time than I deserve of you.

As to medical research, doctor, obviously, again, I think we all agree that there are limited resources on how much we can be doing.

If we were to single out the single largest, glaring problem—and I presume you will agree that the medical research area of gerontology primarily is a Federal Government obligation.

I mean, I am sure States can do some things; obviously, private institutions do.

But if we are discussing the public sector, the bulk of it has to come from the Federal Government.

If you had to prioritize in the area of medical research, where is the glaring lack of effort being made? Where would you spend those limited dollars right now in the area of medical research?

Dr. OSTFELD. Well, in talking only for myself, I think we know more about aging rats and mice than we know about aging people.

And I think we need more research, first of all, that is aimed at understanding what the real problems of older people are, as they live their day-to-day lives.

Second, we need more research directed toward the spontaneous attempts to deal with problems of older people that are springing up.

There are all kinds of fascinating efforts by older people and younger people, by individuals and groups, to try to deal with the population explosion of older people.

And while we have a good deal of anecdotal evidence, we need more information about what is working and what is not.

In other words, we need for science to mirror life, first, and then we need to understand the relative successes and failures of all of these opportunities, all of these different programs that occur.

And I think we will be in a much better situation. A good deal of the budget of the National Institute on Aging is spent for maintaining colonies of older animals.

And I think that while some of that may be properly placed, I am not sure that all of it is properly placed.

I think we also need to interest increasing numbers of physicians and investigative scientists into this field; the number is relatively small, and they are still being recruited from other areas.

But I think we need increased opportunities for training people in these areas at all levels.

Senator DODD. Thank you very much.

Audrey, I wonder if you might briefly comment. We talked about the partnerships of the various agencies involved.

And I think what is terribly confusing to a lot of people who do not work on this area day in and day out, as all of you do, is just the many entities which may be involved—obviously, there are area agencies on aging, the health departments, income maintenance, there is Medicaid, Medicare and who administers what.

How much difficulty do you find there is in coordinating efforts?

How much overlapping is there? What would you suggest be done to try and see to it that the cogs of these wheels work more smoothly or are they working smoothly enough in your mind?

Ms. **Wasik**. In Connecticut, in 1980, the commission on long-term care was established to help grease the wheels, if you will.

We have eight State agencies that deal with human services. They are all represented on the commission on long-term care.

And it is difficult because our funding streams are agency-targeted.

It is difficult sometimes to change our perspective to the broader perspective and see what is happening to our total system; we are so busy determining what is happening within our reimbursement area or a single agency.

So, we do have to step back and look at the broad system, and find out what is happening; how are our regulations impacting on direct care and what does the Medicaid reimbursement system do to our total system and do we coordinate this with home services, be it Federal or State dollars, such as independent living programs.

I see a need for all States to start talking in terms of—and it is not just a Federal barrier. It is a State barrier, also.

I see a need to start talking in terms of developing a comprehensive system with these programs and these dollars at a State level. It can be done, and some States have done it.

We, in Connecticut, have adopted policies on community-based services for the elderly that cross agency lines, so that we are now looking at our own agency policies and saying, "Let us make sure that we meet a statewide policy goal," so that our intake system is similar in one program and another program and that we are not dropping clients in the cracks, even though these programs are there.

I am a proponent of case management. I think the case management system for human services that will not tie individuals up with individuals programs and individual funding mechanisms would help tie this together.

But I think the barrier is not totally on the Federal; I think they are on the State level, too, and we can do something to create a comprehensive system by saying that our intakes are going to be a single entry level and that we are going to develop a case management system to direct our clients where the programs are and where the dollars are.

Senator **Dodd**. I have one more question, and I would like to ask all of you if you would like to comment on this.

In more question and answer periods, if I get any question at all, lately, it has to do with the prospective payment system, the Medicare reimbursement payment and the DRG's. Everywhere I go this comes up.

And many have suggested in the mail—and I do not think I am unique in this regard, I think others are getting this as well—that people are leaving hospitals "quicker and sicker," which is usually the line you get from people when they talk to you about these things.

And they are displacing the chronically ill people in nursing homes and the like.

It is putting tremendous pressure, obviously, on the system, to tie into what we are talking about here today.

And I am just wondering if you might have any comments on whether or not the early discharge is creating problems; can you document that and, if so, what suggestions do you have of ways we can deal with the problem.

Obviously, it is a large problem. I think we could have a hearing just on this one subject.

So, I am going to ask you to be relatively brief because I can see you all kind of getting ready to jump into this one.

But it would be ridiculous here this morning to not talk about DRG's at all, since there is so much interest in the subject now.

So, Audrey, would you want to comment first?

And I will ask the rest of you if you want to add to that, as well.

Ms. **Wasik**. I know that home care, to my right, will have a great deal to say, so let me leave my comments on the institutional side.

DRG's and the early discharge of patients from hospitals is impacting on our entire system of care.

And I checked with the department of health services, hospital and medical quality care division, and asked them, in their inspection, what are they seeing; are they seeing a change.

I said, "I hear things, but are we actually seeing it? Can you document it?"

And, without question, the director of the unit said to me, without question, we are seeing a change in the type of care and the extended skilled care that is needed in our nursing homes, and I know the same is true in home care.

But, without question, DRG's are impacting on the long-term care system, and we cannot ignore that. We cannot ignore that.

The needs of the institutions and the needs of the home care, the cost shift is there, and it must be addressed.

Senator **Dodd**. Dr. Ostfeld, I noticed you were leaving. Thank you very much, by the way. It was very gracious of you to be here this morning.

Ms. **Daubert**. Senator, I agree with Audrey's comments. We have seen a change in the intensity of need level of patients.

They are sicker and they are coming home from the hospital earlier.

However, there is another element that is kind of an underground factor, and that is that more people are being turned away from admission to hospitals, and they never get into the statistics.

They are seen in clinics. They are seen in emergency rooms. And they are told, no, it is not appropriate for admission.

And they are not being admitted to hospitals. They are returning to their own homes.

And I am sure that Joan has clients daily that this happens to.

Ms. **Quinn**. We recently had a situation in one of our offices where a person went to the emergency room, having had an acute heart attack, and was discharged and died in the ambulance on the way back home because the symptoms were not as pronounced as they would be in a younger person, very common in older adults in terms of their presentation of symptoms, when they have certain problems.

So, access to the hospital in the first place is a significant problem, as Betty mentioned.

Senator **Dodd**. Thank you.

Do you want to comment on that, as well?

Commissioner **Klinck**. Just one thing. When we are talking about medical denials, this is one problem that I would like to see addressed. The Federal Government has taken away from the States resources to appeal those denials.

They have reduced a great deal of funding for legal services for the elderly.

And I feel this is an extremely important part of elderly services that nobody ever thinks about.

First of all, when we talk about education, I think we should be training attorneys on how to deal with elderly clients.

They are dealing with elderly clients all the time, and they are not aware of what services are available in the State to address their needs.

Also, I think that we should be supplying some sort of funding to assist the elderly when they want to appeal a Medicare denial.

How do they go about appealing those Medicare denial cases? Let us give them the assistance they need to do that, either by taking them through the whole process or training other people out in the field who deal with the elderly on how they can do it.

When should something be legally denied, for one thing, and what do you do when it is denied?

I think we are not doing enough of that, and I think we have to address that issue. We have to make the elderly aware that there are cases where they should not be denied.

I think we have to train people in the nursing homes and hospitals when to deny, and how to appeal those denials.

I think the people who are admitting elderly, the people who are discharging them, are probably not aware when they should be advising somebody to appeal.

After all, the medical professionals are not saying, "I will not allow you"; somebody else is saying that.

So, they should have the information on hand to give the elderly person and say, "I think this is a case where you could appeal it and this is who you should go see."

And then we should have some more attorneys, legal service developers, if you want to call them that, available to help.

We have one in our department for the whole State, but he is bombarded with calls and cannot really take care of all the problems.

So, I think there should be more funding for legal services around the State.

I think we should be ready and willing and assist the older person in appealing Medicare denials.

And I know this is something probably the Federal Government is not that anxious about because, if we start appealing them, it is going to cost more money.

But I think that, when Government should be paying, elderly should go through the process even if it takes 2 years and appeal it, and then maybe there would be fewer denials.

Senator **Dodd**. Betty, let me ask you a basic question, if I may.

I should say that I am a cosponsor of a number of bills that have to do with Medicare reimbursement that would expand the coverage in a lot of these areas that we are talking about here this morning.

But, frankly, there has been some hostility, and you get the feeling of some hostility to expanding coverage in these areas.

Obviously, I suspect that the reason is, of course, that people ought to be able to do more to take care of their own needs; that this is not something the Federal Government ought to expand its services in.

How would you explain what the reason is, beyond the financial considerations, for this reluctance to expand into these other areas that we have talked about here this morning?

What should we, in Congress, do to strengthen, if you will, the system of home health care beyond the idea of expanding Medicare coverage into some of these areas?

Ms. DAUBERT. Your first question—I think that what happens is, when you look at the statistics and when you look at the outflow of Federal dollars through the Medicare Program, in particular, you see a very rapid growth, and that scares the Federal administration.

However, they become hysterical without looking at the other half of the coin, and that is the increasing elderly population.

Proportionately, the number of home care services, from a volume perspective, have not increased; they have remained stable at between 2 and 2.5 percent since the beginning of the early 1970's.

Now, a lot of people on the Federal level do not want to hear the other side of that coin.

What we are really facing is an explosion in our elderly population.

In addition to that, we are facing the DRG system which, in other parts of the country, have had a much greater impact than in Connecticut.

Even though we might not think so, Connecticut has had a regulatory system in place for about 5 years, so that our average length of stay was 1 to 3 days less than Western States.

So, even though we are seeing the impact of people going home, "sicker and quicker," it is much less than in other States.

When Mary Ellen was talking about more assistance for legal aid, it again brought to mind a thought that I have had several times.

When you look at Medicare in the late 1960's and early 1970's, all people had to have was to be 65, have a Medicare card and, in relation to all levels of care, they could get the service they needed.

The year 1970 was the first time that we saw what is known as reinterpretation of existing guidelines.

And, each year, we have had more and more. And what that has done—if you look at, proportionately, the amount of money that is spent on bureaucratic redtape and hiring lawyers to fight Medicare denials and this kind of thing, if you could take that money and put it into direct service, you would have a lot less expenditure of the Federal health care dollar, I believe.

So, in other words, Senator Dodd, make it simple.

Senator DODD. Lastly, we have requested a waiver, section 2176—I get dizzy from all of the numbers—as well, in the State.

I think Mary Ellen pointed out that there is legislation pending that would make it easier for the State to get these waivers.

And I am a cosponsor of that effort, as well. One of the problems we see with the administration—again, not in a partisan way, but opposing this particular effort—what is the rationale?

I mean, it is easy to say that they oppose it, but there must be some arguments they are raising beyond cost, it would seem to me, in this area.

What are they?

Ms. QUINN. I think it primarily is that they view any expansion of benefits—and they view this as an expansion of benefits—as an add-on; they do not feel that there would be less people using nursing home beds if this program goes into effect, but that more people will use both.

And I think that really is their primary objection at the moment.

Although it has been a terrible struggle for any of the State Medicaid Programs to get this waiver, more and more are finally getting approvals. Unfortunately, you have to use political means to do that.

In our pilot project in Fairfield County, which is just in seven acute care hospitals, we have been able to divert anywhere from 24 to 27 percent of all of the people slated for nursing homes back into the community at a significantly lower cost than institutional case, which is anywhere from $2,300 to $3,000 per month in this State.

So, even if you can delay that placement, you are going to save money in the end.

And we have had many people home for over a year. So, it is a workable program, I think.

And I think if you give enough effort and emphasis to the program, you will empty some nursing home beds.

But you cannot operate the program as a token one.

Senator DODD. I am glad you say it because I think we are not all impressed by the human cost involved.

And we hear Mrs. Kelly or other people like her and, obviously, there is that human element.

But a lot of times, people are not moved by human issues. They seem to be primarily interested in the financial questions.

And what all of you have said here today is that what you are looking at is a significant savings of Federal dollars.

I mean, you are talking about saving money in times of limited resources.

And, frankly, the administration—I want to tell you that there is not any argument that I have been able to hear anywhere that opposes the notion of trying to forestall or delay or prevent people from going into nursing homes.

And as I said in my opening statement and for those from the nursing home industry here today, I am not suggesting in the slightest—in fact, it would be deplorable if we were to lose our nursing home facilities in this country.

The private nursing homes contribute significantly to the wellbeing of people in this society.

But the idea of, if possible, trying to keep people in a home environment makes more sense from the human standpoint.

And the cost savings—and the administration certainly agrees with the goal of cost-saving—of the long-term home care or the community-based care facilities make a lot of sense.

I thank all of you for being here this morning. I have taken a lot of your time, and I have a lot of questions here.

If you have got a couple of more minutes, let me just run down a few of them.

Someone asked here what are the chances of resurrecting the IRA's as a viable retirement plan for future generations.

I would just say briefly here that I do think we are going to be able to maintain the IRA Program to some extent in the tax bill; I think there is a very good chance we will.

We came very close to this in the Senate, a two-vote margin. The House, of course, has retained it.

So, I think there is a good chance that that will be done.

Mary Ellen, there is one for you here. I will just read it; I did not read them ahead of time.

> Congrats on working towards the waiver of Medicare towards extended home care. Will this waiver appeal from home care support systems before hospitalization rather than only after hospitalization? This would be supportive of the prevention of hospitalization.

Commissioner **Klinck**. Yes. The waiver that we are requesting does include elderly entering nursing homes directly from their home. You do not have to be in the hospital.

The program that we are doing now in Fairfield County involves a waiver only—when you are in a hospital and being discharged to a nursing home. Waiver hopes to send elderly back to the community to their own home with services.

But the waiver that they are requesting now in the State of Connecticut will involve people who are also in the community but only those who are applicants to a nursing home.

So, yes, the answer is that it would include people in the community.

And I think that—Joan, you may be more up on that, but I think we feel pretty confident we are going to get that waiver. Do you agree?

Ms. **Quinn**. Yes.

Commissioner **Klinck**. Commissioner Heintz is here. I do not know how far along that has come.

Actually, we are very hopeful that it is going to happen; that people from the community will be included.

Ms. **Wasik**. I would just like to add, if I could, the State of Connecticut has made a commitment to a community-based service program, even if the waiver is denied.

Senator **Dodd**. That is good news.

Audrey, here is one for you. "We have a developer who was given by the State a permit to build a nursing home in conjunction with a congregate living facility. He is now building the nursing home, but there is no site for the congregate housing. He claims he did not get financing together for the congregate housing. What went wrong? The State needs congregate housing, not another nursing home."

I left the name of the developer out; he is not here to defend himself.

Do you know which one I am talking about, maybe?

Ms. **Wasik**. No. And I do not know what went wrong. I am not sure what the bottom line question is, whether or not the CON included both the congregate housing——

Senator **Dodd**. I am going to give you that one. You can go home with that one.

Ms. **Wasik**. I would be happy to discuss it with the author afterward.

Senator **Dodd**. All right.

Ms. **Wasik**. I would agree that we need congregate housing and living arrangements with the support services.

Senator **Dodd**. This is for Mary Ellen, again. And someone from the department of income maintenance can respond to this, too, if there is someone here.

> Is there evidence of discrimination between Medicare and Medicaid patients in nursing homes? As social workers, we need to know how to interpret the new admissions programs going into effect. The burden of this job is on us. We need clarification, unity and consistency on how to implement what the State wants.

Commissioner **Klinck**. Well, I gather they are talking about the new waiting list bill, possibly, which basically states that the nursing homes must keep a record and give a receipt to everyone who comes to a nursing home and signs an application for admittance.

And, therefore, they must be taken in order, and they cannot discriminate whether they are on Medicaid or whether they are private pay.

That particular bill was passed last year, and we have had a committee working on establishing regulations because we know that this can be quite complicated.

The regulations have not been written yet, and we are continuing to look into that bill and writing regulations.

But, basically, I think, in the State of Connecticut, we are very fortunate in that we do not have many cases of Medicaid discrimination, that have been actually reported, anyway.

And this is why this bill was put into effect, where the applicant gets a receipt because, before that, there was no way to check whether there really was discrimination or not.

If an ombudsman went into a nursing home, if there was no list with a numbered receipt, there was no way you could really accuse someone of discrimination because you really did not see a numbered list with the names on it and people could not say, "Well, I was number 18, and this person who was number 40 came in and was admitted first."

So, now, if you do have a number, you can go back and at least investigate it and say, "Listen, my receipt is dated May 11, and this person came in who has a receipt dated May 30. Why was he admitted?".

So, actually, the bill makes our job easier so that we can at least investigate more fairly any cases that might be reported to us.

But, in the State of Connecticut, I think that we are very fortunate. I do not think that we have that many cases of Medicaid discrimination.

Senator **Dodd**. A number of questions here, by the way, were responded to during the testimony involving expanding coverage under Medicare and so forth; there was one here on that.

There was another here on the ombudsmen and expanding the coverage and so forth, home care and so forth, which you have already responded to, as well.

I have one here that does not bear directly on the subject matter, but it is one that is interesting. And I agree with this.

> The Supreme Court made a ruling recently on airlines not having to give special accommodations to any handicapped persons, regardless of their ages. My idea is that people do not have civil rights respected. Am I right?

Well, I think a number of things are going to happen with this one. Mr. Slaven asked this question.

One is, obviously, that there is a significant dollar amount involved.

I suspect that most airlines are going to maintain those kinds of services because it is too financially attractive for them not to maintain it. That is without any action being taken.

However, I would suspect that there may be some congressional activity in this area, as well.

The Supreme Court has ruled that there are ways, either through the regulatory process and so forth, short of absolute mandating, that you can have incentives and disincentives with regard to landing fees and taxation and the like.

So, while it is not mandating that airlines do certain things, there might be enough of the incentive approach for them to do it.

There is already some thinking going on in that regard, as well.

I will just tell you that I just received a note here that the Supreme Court, this morning, has overturned the Gramm-Rudman Act by a vote of seven to two, just the provision as it relates to the Comptroller General, which is what the lower court has done, as well.

That would mean, it seems to me, that Gramm-Rudman is still in effect. Some of the teeth are gone. Not all of the teeth are gone, but some of the teeth are gone with regard to—you may recall there was a battle over who would come up with the alternative numbers if the Congress and the President were unable to reach an agreement.

And we settled on the Comptroller General of the United States.

The Supreme Court, upholding the lower court decision, I presume, was based on the lower court logic that the Congress of the United States, because we are a separate branch of the Government, could not give executive branch power to a legislative branch officer, the Comptroller General.

So, we will have to come back and find some new entity to meet that requirement of Gramm-Rudman.

In any event, I do not know much about the decision than that.

Anyway, I thank all of you for coming. Mrs. Kelly, you are wonderful to be here. We hope you continue to take care of that good husband of yours. He is lucky, as I said, to have you. And we hope you get some respite care to continue along those lines.

And, again, I thank our distinguished panel here, with the tremendous work they do on the subject.

These comments this morning will be extremely worthwhile to the Senate committee in Washington, as we try to come up with answers to these problems.

So, I thank you all for being here, and this committee is adjourned.

[Whereupon, at 12:25 p.m., the committee was adjourned, subject to the call of the Chair.]

APPENDIX

MATERIAL RELATED TO HEARING

Testimony of

Ruth D. Abbott, MPH, RN
President/Executive Director
Visiting Nurse And Home Care, Inc.
146 New Britain Avenue
Plainville, Connecticut 06062

Thank you for asking me to submit testimony for a hearing on "Meeting the Health Needs of Our Senior Citizens: Providing a Comprehensive and Compassionate Long Term Health Care Program."

I am the President of Visiting Nurse And Home Care which serves both the Hartford and Waterbury regions of Connecticut - a population of some 680,000. Most of the municipalities in this region have a higher than average percentage of elderly. Services and the funding for them are not now adequate and, with the growth in the older population - especially those 75 and older - we will see an increasing gap between need and available services.

Home and community-based long term care services are not uniformly available across the State. My own Agency has the most comprehensive array of services of any agency in the State and, even here, more are needed. Those available through Visiting Nurse And Home Care include assessment and counseling, acute and high-tech nursing care when needed, hospice care, therapy services, personal care, homemaker/home health aide service (Tri-Care), home help and chore handyman services, Alzheimer and respite services, medical social work, friendly visitors and meals on wheels. There are some 700 staff (full and part-time), and services are provided 24 hours a day, seven days a week. All services are greatly enhanced by more then 1,000 volunteers and the many family members and friends who give untold hours of caring. Even though over 270,000 home visits were made last year - 84% of these to people over 60 years of age - there are many in our 17 municipalities whose needs for services are not being met. Major reasons for this are lacking or inadequate funding mechanisms, including inability to self-pay because of living on a fixed income, slow development of long term care insurance, insufficient knowledge about home care and how to access it. The social support services (those which help to postpone or prevent institutionalization) have long been very difficult to provide since there are practically no funding resources for these. In the past two years, with Medicare cutbacks, even the acute episodes which long term care clients experience are often covered so inadequately that the amount of service needed cannot be provided. This is true even though private sources of funding have been most generous in helping us meet service needs.

Community services in senior centers, senior housing, etc. are also inadequate. It is our belief that preventive services, provided even before age 60, will help to reduce the amount of long term care needed later on. Towns have only limited funds to pay for such preventive services.

Even though Visiting Nurse And Home Care has the most comprehensive array of services in both home and community settings, there are still services that we have not been able to provide which are needed; for example, day care and transportation. Studies made by a regional health consortium, the Community Council, and other such groups, point up the need for an increase in social support services. A recent estimate (1983) by the State Department on Aging is that some 4,700 elderly persons annually are inappropriately at risk of institutionalization due to insufficient supportive services in the home. Regional data show a need for more nutritional and meal services, homemaker/chore services, counseling, respite, case management, recreation, home maintenance, congregate and other housing arrangements and financial services.

The federal government does need to work toward filling the gaps and producing an integrated long term care system. This system needs to be linked to other health care systems so that people have access to a full range of services. Medicare reforms are important because of acute episodes that long term care clients have. I would ask for support for:

1. S-2494, introduced by Senators Bradley, Heinz and Glenn, which would restore the ability of home health agencies to aggregate costs, mandate hospital discharge planning, and require HCFA to follow the Administrative Procedures Act.

2. S-778, introduced by Senator Heinz, which would define intermittent care to include up to 60 days of daily care, and thereafter under exceptional circumstances, with monthly physician certification that care is reasonable and necessary.

In addition, support is needed for demonstrations, evaluation and development of models of community-based long term care. The need for a more coordinated and efficient approach to long term care has been recognized for some years, but more demonstrations are needed.

I also support a recommendation that third-party financing be studied in depth. Good long term care will never be inexpensive. To the extent that the goal of maximum functional independence is substituted for the "custodial" approach, it will become more expensive. Third-party financing is just as essential for long term care as for acute care. More study is needed as to whether long term care should be incorporated into Medicare. Certainly, the outcome should be a financing system that provides protection from impoverishing individuals, and allows for combining private and public resources. It should also provide incentives for providors to keep costs at reasonable rates.

Support is also requested for incentives for people to become better educationally prepared in gerontological care. Physicians, nurses and other helping people need more preparation to deal with the issues of long term care and to provide the highest-quality, compassionate care to long term care clients.

Thank you for allowing me to send this testimony. Please call on me or Visiting Nurse And Home Care ((203) 747 -2761) if we can be further helpful.

Ruth D. Abbott/dw
7/3/86

canpfa

Connecticut Association of Non-Profit Facilities for the Aged • P.O. Box 90 • 110 Barnes Rd. • Wallingford, Connecticut 06492 • (203) 269-7443

PRESIDENT
ROSALIND BERMAN

CHAIRMAN
CURTIS MILTON
MASONIC HOME & HOSPITAL
MASONIC AVENUE PO BOX 70
WALLINGFORD CONNECTICUT 06492
265 0931

VICE CHAIRMAN
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POPE JOHN PAUL II CENTER FOR HEALTH CARE
33 LINCOLN AVENUE
DANBURY CONNECTICUT 06810
797 9300

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200 LEEDER HILL DRIVE
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281 6745

TREASURER
DAVID BAILEY
MCLEAN HOME
75 GREAT POND ROAD
SIMSBURY CONNECTICUT 06070
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235 5432

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CONNECTICUT BAPTIST HOME
292 THORPE AVENUE
MERIDEN CONNECTICUT 06450
237 1206

MARIANNE KEEVINS
THIRTYTHIRTY PARK INCORPORATED
3030 PARK AVENUE
BRIDGEPORT CONNECTICUT 06604
374 5611

IRVING KRONENBERG
HEBREW HOME & HOSPITAL
615 TOWER AVENUE
HARTFORD CONNECTICUT 06112
242 6207

DAVID MacNEILL
ELIM PARK BAPTIST HOME
140 COOK HILL ROAD
CHESHIRE CONNECTICUT 06410
272 3547

MOLLY SAVARD
THE BRADLEY HOME
320 COLONY STREET
MERIDEN CONNECTICUT 06450
235 5716

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Statement from the Connecticut Association of Non-Profit Facilities for the Aged on the availability and sufficiency of existing home and community based long-term health care services for the elderly in Connecticut.

Home and community based long-term health care services for the elderly have been the focus of concern and action by the sixty-six not-for-profit members of the Connecticut Association of Non-Profit Facilities for the Aged for a number of years.

The "graying of America" is the result of a dramatic increase in the life expectancy. The 85 plus population is the fastest growing group in the nation, according to the Department of Health and Human Services. There has been a significant rise in the 85 plus "senior boomers" in Connecticut.

Some form of long term health problems or chronic illnesses affect more than 47 percent of the elderly population. Despite that fact, one in ten of the "senior boomers" lives alone.

All of this has significant implications for public policy. The frail, elderly, who live alone, need access to decent health care and vital social services.

In Connecticut, the demand for community based services exceed the supply and the ability to pay for them.

The directors of non-profit nursing homes and homes for the aged in Connecticut have devoted their energies to present viable options for the aging population. The emphasis is on providing quality support services to enable the elderly to remain independent and in the community for as long as possible. Many of the non-profit facilities in Connecticut offer a continuum of care and services for the elderly beginning with options for healthy older people and progressing to those who need increasing degrees of care.

Senior housing includes many options for people at a variety of income levels. Senior apartments may offer services such as group programs, and/or congregate meals. Continuing Care Retirement Communities offer a complete range of housing and care in a single setting, ranging from independent living to twenty-four hour nursing care. Assisted living facilities provide more services than senior apartments to senior citizens who need some attention on a twenty-four hour basis, with perhaps some medication oversight.

Some non-profit facilities and organizations offer community services which include adult day care, respite care, meals-on-wheels, hospice care, home health care, and information and referral programs.

Skilled nursing facilities provide compassionate twenty-four hour care, which includes physical therapy, rehabilitation programs and other specialized skilled and professional services for chronically ill and disabled elderly.

Intermediate care facilities provide personal care and assistance with daily living activities, as well as less intensive nursing care than a skilled nursing facility, to the aged who are unable to live independently.

Although the demand for community based services has increased, so has the need for skilled nursing facility beds. Policies of the federal and state governments, which have mandated prospective payment systems and diagnostic related group hospital reimbursement, have resulted in an increasing number of very frail, very sick elderly patients being prematurely discharged from hospitals and needing high intensive care in skilled nursing facilities.

Medical science has achieved remarkable results in increasing life expectancy. Public policy must be directed to providing incentives to insure that the needed care and support servies will be available to our older population. Years have already been added to life - now government must make sure that life is added to the years.

Rosalind Berman
President

Dear Senator Dodd:

Licensed Homes for the Aged meet a very important need in society's attempt to provide comprehensive and compassionate long-term care. We provide one of the least restrictive environments of institutional living. Many of our residents are very independent and active, participating in family and community activities while allowing the families or residents themselves to be relieved of the monumentous task of 24-hour a day custodial care. Yet, it is alarming to the members of the Connecticut Association of Licensed Homes for the Aged* that many State and Federal long-term care officials and professionals are not even aware of our level of care; the services we provide; the cost of our service; and do not have comprehensive or valid statistics on Homes for the Aged, neither past nor present; nor are they aware of the imminent issues concerning the survival of our homes. Thus, if they are not aware of the issues, they cannot help resolve our problems, assist in strengthening our industry, or better utilize our level of care. The purpose of this paper is to better familiarize the U.S. Senate Special Committee on Aging with Connecticut's Licensed Homes for the Aged.

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* The Connecticut Association of Licensed Homes for the Aged is a non-profit organization which was founded in 1985 and incorporated in January, 1986. Our membership currently consists of 56 of the 138 licensed Homes for the Aged in the state. Among our goals: to build a better working relationship with the facilities providing care at our level and the State and Federal agencies that regulate us; to gather information and knowledge important to our industry; to encourage and carry out the function of staff training; to share new ideas and help solve problems; and, to represent our members' point of view on pertinent matters.

There are approximately 3,581 licensed Homes for the Aged beds in Connecticut. The facilities range in capacity from as few as 4 beds, which is the case of a home in Colchester, to as many as 127, which is the case of a home in West Hartford. The vast majority of our homes are licensed for 25 beds or less, considerably smaller than most Intermediate and Skilled Nursing Facilities. Our physical plants are also much older; in fact, informal research estimates that most of our original buildings (before any additions) are 57 years old or older. This has posed some obvious problems at some homes due to what seems like constant additions of new standards and regulations governing the actual physical plants. Because of the age and layout of most Homes for the Aged, it is becoming increasing difficult, and in some cases actually impossible, to fully comply with those same codes that also apply to nursing homes.

Most facilities at our level of care were originally built as large private residences; are 2½ story, wood-frame buildings; and are located in areas zoned as residential. The majority of our bedrooms are double occupancy; however, there are some private rooms, and a few of the older homes have multiple-bed bedrooms. Most are family-owned and operated businesses, where an owner is usually the manager, and it is quite common due to our small size to have a number of related parties on staff.

Despite the fact that we are called licensed Homes for the Aged, the average age of our resident is only 59 years old. These residents are usually placed in our homes through individual families, by state and local hospital discharge planners, occasionally by a physician, and sometimes from a facility of a higher level of care who has been instructed to downgrade a patient. We render care and services to those in need who are eligible for State medical assistance pursuant to Connecticut's Medicaid program, and also to those who can pay for their care from their own resources.

Unlike patients in nursing homes, all of our residents must be ambulatory; that is, they must be physically and mentally capable of walking a normal path to safety without the aid of another, including the ascent and descent of stairs. A physician must attest to this, and also that our residents are in no danger of harming themselves or others. A typical resident may be an elderly person, who, for some reason, is unable to remain in their own home or with family members, if any; or in many cases, another adult who has a history of a mild mental disorder who has been deemed disabled and who is receiving S.S.I. benefits.

We do not involve the provision of skilled nursing or intermediate care, but rather utilize the services of non-professional personnel. On-the-job training is provided to our staff for special procedures, and we coordinate and utilize outpatient medical and social services to ensure that our residents get the care warranted. We have an attendant on duty 24-hours a day, 7 days a week, and frequently he/she has a background of working with the elderly or disabled. The services provided by staff include supervision of nutrition, supervision of the self-administration of medication and activities of daily living, such as dressing, bathing and shopping. Although, as in all businesses, there are those few who, unfortunately, spoil it for the rest by their non-compliance and negative attitudes, the vast majority of our homes honestly strive to provide safe, healthy, and socially enriching atmosphere for our residents. We provide a less restrictive environment than a nursing home, and most of our residents are very active, engaging in truly meaningful activities. Our residents are treated with dignity and respect and they maintain their individuality and as high a degree of independence as feasible.

This quality, long-term care is provided for those appropriately placed in our licensed Homes for the Aged, at about 1/3 the cost of comparable nursing care facilities, group homes, congregate housing centers, and in some cases, even adult day care centers.* The average per diem rate for a licensed Home for the Aged in this state stands at $25.22. (This information was gathered from Policy Transmittal #PA-86-9 of the Public Assistance Administration.)

Despite the potential cost savings, a survey of 40 homes of our Association, conducted in May of this year, indicated our utilization to be only 82%, while other levels of care are experiencing considerable waiting lists for placement. This not only poses an obvious cash flow problem in the operation of the facility, but comes back again to affect the reimbursement rate, as all allowable costs are computed at 90% utilization for all levels of care.

It is our understanding that the State of Connecticut is making a concerted effort through the D.I.M. Preadmission Screening Project to establish preadmission screening programs which classify persons by their care needs. The project is predicated on recognition of strong potential value to clients, and savings of public funds that result from offering appropriate placement in multiple levels of care. Unfortunately, other than the information our Association has compiled, by direct survey and questionnaire forms, there are few statistics to establish a clearer profile of our resident population by age, sex, payment method, level of functioning, type of dependency, source of admission, length of stay, and destination at discharge. It would seem that gathering information on the population currently served by Homes for the Aged would greatly benefit the State's efforts to plan for the future. We feel Connecticut has placed itself at a disadvantage by not maintaining this same comprehensive data on populations and services in Homes for the Aged as for nursing homes. The Connecticut State Department of Health Services currently mandates collection of data on Skilled Nursing Care Facilities, Intermediate Care Facilities, and community nursing services, but not for our facilities.

In conclusion, we would like to have health care professionals, social workers, and regulators, recognize the contribution we can further make to the long-term care system. We ask the Health Department and all relevant agencies to better utilize our facilities to help care for Connecticut's increasing population of ambulatory residents in need of custodial-type care, when a nursing home may not be the answer.

The Connecticut Association of Licensed Homes for the Aged and its member facilities are willing to work cooperatively with the U.S. Senate Committee on Aging, and assist in any way possible. We not only have concern for our livelihood, but also sincere concern for the well-being, comfort, and morale of our residents.

Respectfully submitted,

Michael F. Spada, President
Connecticut Association on Licensed
Homes for the Aged, Inc.

The following written testimony is submitted as part of the hearing record for a field hearing of the U.S. Senate Special Committee on Aging held on July 7, 1986 in New Haven, Connecticut:

I am Bob Congdon, Assistant Director of the South Central Connecticut Agency on Aging, located in West Haven, Connecticut. Our agency is designated by the State of Connecticut to carry out the functions of an area agency on aging as defined in the Federal Older Americans Act. We are one of five Area Agencies on Aging (AAA's) in Connecticut and one of six hundred and sixty across the country.

The Older Americans Act defines four functions for AAA's:

- planning, including determining the needs of the older population, particularly those most vulnerable because of physical health, social or economic needs.
- coordination of resources in order to foster the development of a comprehensive system of community services which enable older people to maintain their independence as long as possible.
- advocacy efforts to educate older people, legislators and the public about issues of public policy affecting older people.
- Funding. We are responsible for distributing approximately $1.5 million in Federal Older Americans Act funds. The largest amount, Title III-C goes for congregate meals (approximately $682,000) home-delivered meals (approximately $211,000).

The $580,000 in Title III-B funds a variety of community based supportive services as follows:

In home	38%
Adult Day Care	21%
Medical Transportation	25%
Legal	10%
Employment and Health Serv.	6%
	100%

In-home services include respite and chores such as heavy cleaning, minor home repair and yard work. The largest amount of the In-home budget is used to purchase from Connecticut Community Care, Inc. (CCCI) case management and the accompanying package of services to maintain older people in their homes. Our entire III-B budget would not be sufficient to address the waiting list for managed long term care in South Central Connecticut. Instead, we use III-B to plug gaps in services and develop new services.

Perspectives on Long Term Care

Long term care has traditionally been interpreted as those services provided on a long term basis to chronically ill or impaired persons in institutions. As a result, long term care was commonly viewed as solely delivered by the medical professions. From our experience with planning and funding services for older people, there are two points I want to make about community based long term care.

First, many of the needs of impaired older persons who seek to remain at home are non-medical. They include help preparing meals, dressing, homecleaning, minor home repairs, shopping, transportation, and supervision while primary caretakers have a break or respite. These are needs which can be met by para professionals (such as homemakers, companions and chore workers, by family members or by volunteers).

The need for non-medical social supports is evident from the service pattern of CCCI, which funds only services not reimbursed by Medicare, Medicaid or other sources. CCCI funds are used primarily to purchase homemaker, companion, home health aide and adult day care services.

This pattern is also evident in Connecticut's developing Nursing Home PreAdmission Screening Program, operating on a pilot basis in Fairfield County. In this program, patients are screened prior to nursing home admission to determine if they will become Medicaid eligible within six months of nursing home entrance and, if so, whether they can more appropriately and cost-effectively be cared for at home. The list of services funded under this program includes many which are non-medical: homemakers, companions, meals on wheels, foster care, respite and adult day care among others.

Second, I want to comment on the value of Adult Day Care in meeting long term care needs of older people in the community. Adult day care is a relatively new service in this country, and many older people and their caregivers are not yet aware of it as an option. Adult Day Care refers to a structured group program for adults, based on an individual plan of care which may include counseling, meals, health and medication monitoring, exercise, crafts, recreation, bathing and transportation among other services. Centers are generally open five days each week, although we fund one model program which is open seven days per week, every day except major holidays. Many centers are serving substantial numbers of Alzheimer's patients.

Why is Adult Day Care a value? It provides a whole range of services, depending on individual needs.

- It provides important opportunities for frail older people to interact socially in ways they can not while being cared for at home.
- It provides respite for family care givers.
- And of particular importance to this committee, it can be very cost-effective. Adult Day Care in our area is averaging $30/day, which averages between $4 and $5 per hour. This compares very favorably with the going rates of more than $10/hour for home health aides who provide personal care under a nurse's supervision, and average rates of more than $8/hour for people serving as homemakers or companions.

In addition, adult day care clients get the package of services and social benefits previously mentioned.

Recommendations for Federal action:

- Continue to support Medicaid waivers which enable states to develop community based long term care systems which enclude both health and social support services.
- Support development of Adult Day Care with both start-up funding and reimbursement.
- Increase Older Americans Act funds for home-delivered meals. Despite making use of all third party reimbursement and local fund-raising efforts, the home-delivered meal program serving the Greater New Haven area currently has fifty-three (53) people on the waiting list. The only way this waiting list can be addressed with the existing level of Title III funding is to cut congregate meals or III-B supportive services.

- Maintain Federal support for UMTA subsidies of handicapped-accessible transportation for medical trips and other needs.
- Expand funding for community-based long term care through Medicare, Medicaid, Older Americans Act, and the Community Services and Social Services Block Grants. Cutting such funding in an effort to reduce the Federal deficit is short sighted, since it leads to more costly expenses out of the Medicaid budget to pay for institutional care.

Thank you for the opportunity to offer my comments.

CONNECTICUT ASSOCIATION OF HEALTH CARE FACILITIES, INC.
Suite 18, 131 New London Turnpike, Glastonbury, Ct. 06033

July 16, 1986

(203) 659-0391

Christopher J. Dodd, Senator
Senate Chambers
State Capitol
Hartford, Ct. 06106

RE: PUBLIC HEARING STATEMENT - JULY 7, 1986
BELLA VISTA COMMUNITY, NEW HAVEN, CT.

Dear Senator Dodd:

Thank you for this opportunity to submit a written statement relative to the availability and sufficiency of existing home and community based long term health care services for the elderly in Connecticut. I represent the Connecticut Association of Health Care Facilities, a non-profit organization representing both investor owned and not-for-profit long term health care facilities in the State of Connecticut. Our organization represents approximately 200 facilities that offer various levels of long term care in our state.

Health care and personal service delivery to the elderly should not be a series of fragmented, independent service components without communication, knowledge, or cooperation between them. The physician's office, HMO outpatient clinics, acute general hospitals, long term care institutions and home health care should be part of a single program to maximize the potential of an individual to not only maintain the optimum health level they are capable of attaining but in addition to enhance as far as it is possible, the quality of life for the individual involved. There has been basic problem areas that have hindered this effort:

1. The lack of any organized coordination services organization.
2. Minimal home health and personal services available.
3. Sufficient funds to bring the program objectives to implementation.

The "Triage" experiment that ran several years in central Connecticut showed what could be done when all three elements were available.

There is no of competition between the various components. The patient who is cared for in an acute general hospital, the patient who is cared for in a long term care institution, and the patient who is cared for at home are three distinct clinical entities. All studies that have been done, including those by the Health Care

A non profit organization of proprietary and non proprietary long term health care facilities dedicated to improving health care of the convalescent and chronically ill of all ages. An equal opportunity employer

Financing Administration and the GAO, have shown that the elderly whose needs can best be met by utilizing the services of a community based organization are:

a. usually in their seventies or younger,
b. require only periodic and minimum health care services,
c. generally have a standby support system in the form of a spouse or child,
d. require minimal assistance in the four areas of ADL (feeding, bathing toileting, and mobility).

Patients housed in long term care facilities are generally:
a. older (the average age is 84.6 in Connecticut),
b. sicker, almost all have come as direct transfers from acute general hospitals with severe medical and /or surgical problems,
c. suffer frequent periods of disorientation and/or marked sensory deprivation,
d. frequently have minimal or no family support systems that can be relied upon on a regular basis.
e. suffer from severe ADL dependency in at least two areas.

The less sick the individual and the greater support services that are available to them from the family and spouse, the less personal time and attention of care attendants is needed. This makes the cost effectiveness of community based services a sensible and humane approach to this segment of our elderly population. Indeed, if one were to view the service and time components that an elderly individual might need as one choosing and picking from a smorgasbord of such components, one would find that the fewer the services and the less the time involved, the more appropriate community services are and the less appropriate institutionalization. However, there is a point reached where the time, cost, and the maintenance programs exceed a cost effect model. It is then that the institution becomes a viable alternative to independent living. For example, with a home health aide costing between $8.00 and $10.00/hour, one eight hour day of continuous aide time results in a higher cost than the vast majority of institutions in Connecticut. When one adds to that visiting nurse services running at $30 to $45 a visit and the cost of food, utilities, entertainment, janitorial, shopping, and other services one can see that it takes very little to make the individual move quickly from the area of independent living to requiring institutionalization unless there is a real base of cost free support available. However, if an elderly individual is residing in a relative's home where the basic costs of food, clothing, and shelter are absorbed by the relative - the elderly person's resources can extend far beyond the normal expectations and delay or perhaps permanently avoid institutionalization.

We believe the long term care industry has a great deal to offer the emerging home health and community based service industry. There are years of experience and learning that have gone into the development of geriatric nurses, dieticians, consulting pharmacists, physical therapists, occupational therapists, social workers, speech therapists, and a host of others with specific expertise. We believe that the long term care institution could not only be a resource to these developing community based services but indeed might be able to develop, with some assistance and encouragement, an adjunct service component for the elderly on an outpatient basis. For example, two very important features of an effective community program are:

1. Day Care - when effectively carried out in an organized program and in an appropriate setting it allows an elderly person the ability to socialize with their peers in a protected environment. The opportunity for any person (in particularly, the elderly person) to communicate and interact with a variety of people is absolutely essential to their mental and, in many cases, their physical well being. The problem is many day care centers are oriented primarily to the active and mentally sound elderly. They are inaccessible from a transportation standpoint for the badly disabled and lack the environment and staff to deal with the somewhat disoriented elderly. To develop the services necessary, create proper environment, and hire the appropriate staff may be too expensive or too difficult for most free standing day care centers. Many long term care institutions already have the potential to develop day care programs to meet the needs of the "difficult" day care elderly client. This is particularly true in semi-rural communities which are so common in Connecticut and where the only real health resource is the local long term care institution.

2. Respite Care - another very important aspect of the need for the community service health plan is that of respite care. The caregiver, particularly the "sandwich generation", needs periodic respite from the emotional draining that occurs from the caring for an elderly loved one who is degenerating both physically and mentally. Respite care is an interim program of care for a period of days or perhaps even weeks allowing the caregiver emotional and physical release. This could allow an elderly individual many more years in a home setting. Unfortunately, our members experience is that once the elderly person is out of the home, the placement frequently becomes permanent. Particularly when the elderly is confused, severely ADL dependent, or most important incontinent.

One of the great tragedies that has emerged from the current governmental policies is the patient who receives no care at all. The DRG system has resulted in elderly individuals being brought to hospital emergency rooms who are not sick enough to be admitted nor well enough to go home and certainly not eligible for a long term care institution. These individuals are sent to an inadequate or nonexistent care milieu in their own home. There they deteriorate and frequently become a permanent long term care institution admission. If better, more responsive, home care services were available, some of these admissions could be prevented.

The DRG's have brought much sicker patients much sooner into a long term care institutional setting. These elderly patients are at a much more fragile state in their convalescent period and frequently require far more intensive rehabilitation, nursing services, and social work assistance than has been traditionally associated with the long term care institution. Unfortunately, the system addressed itself only to front end savings at the acute care institution not responding to the increased costs for staff, equipment, and supplies at the long term care institution. The long term care institution has been forced to develop a relatively higher level of technology with the use of electronic cardiac monitors, complex respiratory support equipment, kidney dialyses equipment, intravenous therapy, etc. This means not only more equipment and more staff but also better prepared staff. Staffing is a key problem, particularly in Connecticut with its extremely low unemployment rate and far more glamourous occupations to attract the available working population. The development of more community services will, despite its many advantages, result in fierce competition for staff with higher costs for all components. Therefore, as we develop more service delivery components, we should precede such development with more schools of nursing, students in physical, occupational, and recreational therapy, pharmacists interested in geriatrics, and more social workers oriented to the needs of the chronically ill and incurable individual.

In summary, we believe that there is a very large unmet need for community based services for the elderly. These services, if effectively created, monitored, and funded can improve the life and comfort of many elderly patients. However, we have some reservations:

1. There is a perception that a cost savings will result from these programs by reducing the long term care institutionalized population. However, the research has indicated that:
   a. the unmet need for care will quickly fill the delivery capability of community agencies,
   b. families who are caregivers will turn more and more to outside resources as they become available including government funded programs,
   c. the patients in long term care institutions are not the same population and should remain more or less constant in total number.

2. Those long term care patients of the future will be sicker and require more care, therefore, more funding, not less will be needed - "you can't rob Peter to pay Paul".

3. Quality of care where there are no standard evaluation tools can be a real problem. We know from experience that when there is sudden and unprecedented growth in a care giving field, severe problems of quality control can occur which effect even those not directly responsible for the problems.

4. Monitoring - the ability to monitor and regulate this diverse service delivery system will exceed the available resources of state agencies. Connecticut has shown that 90% of all abused or neglected elderly are in home settings. Ombudsman, health department, social services departments will need to expand.

5. A diminishing supply of existing health care workers of all kinds will make every component of the delivery system vulnerable to fierce competition.

6. The availability of a third party payment for long term care - home based or institutional based - is still missing. The elderly population, present and future, needs someway to protect themselves from poverty and public dependency. Whether those programs are in the government or private sector, or a combination, is not relevant. The horror of the remaining spouse forced to go hungry and live in squalor because their beloved husband/wife is chronically ill should not be tolerated in our society.

Thank you for the opportunity to submit this material. If we can be of any other assistance, please don't hesitate to contact us.

Yours truly,

Louis J. Halpryn
Executive Vice President

LJH/acs

Meeting the Health Needs of our Senior Citizens

Providing A Comprehensive and Compassionate Long-Term Health Care Program

It is self-evident that individuals who exist on fixed incomes within a financial environment of ever-increasing inflation will find it increasingly difficult, if not virtually impossible, to provide for their most basic needs. The elderly population of New Haven is no exception. Countless others exist on fixed incomes slightly higher. Their purchasing power diminishes daily as the rate of inflation rises. For both of these groups and also for those elderly who are slightly more economically secure, most of their financial resources are needed for rent, food, and essential articles of clothing. Little remains for other needs.

Health problems are higher among the elderly than any other segment of the population. While Medicare and Medicaid programs cover certain needs of certain populations, many elderly persons have medically-related needs in which they lack the resources to fulfill.

While a medical condition is stablized in many instances among the elderly, the condition remains chronic, thus requiring comprehensive long term expensive care. Due to Federal and State policy these individuals are placed in nursing homes. Comparatively, "home care" delivery programs have proved less costly than institutional care and need greater legislative attention since expansion of these programs would assuredly save tax dollars. Most importantly, such programs keep the elderly at home who would otherwise be placed in nursing homes under the present health system. The present long term care program fosters and excessive reliance on costly medical and institutional care; studies have shown that a high of 40% of nursing home residents would have been able to remain at home if appropriate services were available.

Of New Haven's total elderly population aged 65 and over, a recent study showed that 36.8% had some degree of difficulty in performing certain tasks of daily living without the assistance of others.

There are relatively few means to coordinate and manage the broad array of services that are needed by an elderly who suffers from chronic health problems. The cost of long term care and the elderly population are both increasing. The need to resolve these problems is urgent.

State and Federal resources must be targeted for alternative measures to institutionalization. Legislation must be enacted to broaden Medicare and Medicaid to include catastrophic coverage for those individuals who require long term care. At present, there are approximately thirty thousand (30,000) persons in nursing homes and Connecticut is facing a shortage of beds unless alternative facilities are developed. Home and community based long-term health care services cost in excess of $800.00 per month as compared to institutional costs in excess of $1,300.00 per month.

Additionally, emphasis at the Federal level must include home-maker services; adult day care; home delivered meals; and respite care.

The goal of home care and community based programs is to foster independence, not dependence of government support.

Submitted by:
Elaine Whitmire, Director
Department of Elderly Services
New Haven, Conn.
06515

Statement on Municipal, Religious and Community Group Contributions Toward Longterm Healthcare Needs of the Elderly Prepared for Senator Dodd's Senate Special Committee on Aging Hearing in New Haven on July 7, 1986:

To me, one of the saddest aspects of our current long-term healthcare system for the elderly is the rapidly increasing number of middle-income elderly who have been pauperized by the system and are now living in nursing homes on Medicaid. Many of these individuals have been reduced to a state of complete dependency on the nursing home staff and, oftentimes, members of their family.

I do not wish to turn this statement into a polemic against our nursing homes. They are needed by the society and perform an invaluable service. However, it is time to rethink the system, especially as the frail elderly, 80 plus members of our society, increase significantly in numbers with the odds that one of each four will move into skilled nursing facilities.

The purpose of these comments is to raise some of the issues, make some suggestions, and try to suggest a role for the federal government in the overall process:

First, let me point out that the top 10%-15% income group of the elderly really have no problem with this issue. They can hire all the help they need to live at home or they can move into a high-cost CCRC, where they pay sizeable entry fees which, in effect, buys them long-term care insurance in these attractive continuum of care facilities.

However, my concern is the middle income group--those who have worked through the Depression, sent their children to college, put away a nestegg oftentimes only in the value of their home, and are not in that group in our society with sizeable pension benefits. Many have retired before building up the kinds of pension benfits we are seeing among the 55 and younger group at the present time. Moreover, when faced with heavy long-term health care costs for themselves or a spouse, spend down their assets and then lose their pride and independence with the inevitable shattering decision to pauperize themselves in order to receive these needed services.

What can we do faced with this kind of a dilemma?

1) Obviously, it is too late to develop a viable long-term care insurance program for the 60-plus group unless the insurance companies can develop a program where the costs can be spread among all age groups. If this were possible and it were launched within the next year or so with government sponsorship, it is possible that the financial agonies for this group could be alleviated to some extent so that as much independence as possible could be retained.

2) We also must recognize that individuals afflicted with diseases such as Alzheimers really can not function in the society without most of the support systems provided in more skilled nursing facilities. On the other hand, have we explored in Alzheimers research such projects as the Australians have been developing in which patients have moved into community homes where individuals are allowed to carry out many of the functions of daily living up to their capacity with proper supervision?

3) What strikes me as the most intelligent way to proceed is to research along the lines of the survey we did in Middletown, Connecticut sponsored by a grant from the Connecticut State Department of Human Services. (A copy of the survey instrument and summary of the study and recommendations are an attachment to this memorandum.) Essentially, we analyzed all of the various services for the elderly in our community, reviewed demographic data based on the 1980 census, and ended up with a reasonably clear current picture of and the projected situation of our various 60-plus population cohorts by the year 2000. We then developed a study of housing, outreach, and transportation needs, and have made specific recommendations to the Mayor and the Common Council to continue this research and to permit Middletown to be a community where our older citizens can age "in place" gracefully.

Nowhere have I seen this detailed type of analysis. It strikes me that much of our public policy especially through Area Agencies on Aging, responds to scattered individual requests rather than to careful public analysis and planning by our local communities. There are exceptions, such as the community project in Greenwhich, CT, and a very exciting program in Oshkosh, Wiconsin, where a group of citizens have organized to do careful long-range planning for their seniors. However, without the detailed information and analysis in individual communities, we have little to rely on for public policy. Our project was inspired by a comparable program in Odense, Denmark where the whole community was sensitized to its aging population. Decisions were made to stop all nursing home placement, except for desperate emergency situations, and a complete network of support services often on a volunteer basis from one older person to another was organized to provide a hospitable environment for independent living as long as it was physically possible for the individual. This is the type of model we should set as our goal and work to achieve.

4) Another very exciting initiative based on our own experience is a project which we developed in Middletown with a major local pharmacy. We developed a program considerably beyond the standard 10% senior discount. It was consumer education on wellness and various prescription drug needs for the elderly. Next month, because of the large Italian population in Middletown, we will translate the monthly "Newsletter" and education program into Italian for the Italian-speaking members of our community. This is the type of initiative which we often forget. Nor do we realize the impact of our local pharmacists in the area of health and wellness programs. The same approach can be used by our local hospitals, our walk-in clinics, and even through a more-coordinated effort among the physicians in our community. The key is to sensitize the community to these issues and mobilize all of the resources in a much more extended educational program.

5) Probably one of the most exciting developments which I have observed has been the growth of the Interfaith Caregiver programs in Connecticut and throughout the country. Many of these were already in place at the time of the Robert Wood Johnson Foundation grants 3 years ago. But this program has done a great deal to encourage and strengthen these efforts and to try to replace the loss of the large number of family caregivers which, through the years, have been providing most of the support for our frail elderly. Statistics indicate that most care for the frail elderly is done by family members, almost 80%, and often this is either the daughter or the daughter-in-law of the frail elderly. However, how are we going to handle these increasing needs as more and more of the daughters and the daughters-in-law are working?

There is no doubt that we have a tremendous reservoir of active young-olds who can work with other individuals in a range of non-medical programs of support for the frail elderly living in their own homes. Often, a weekly escort, where the caregiver drives the person to the dector, to the food store, and possibly one visit a week by a homemaker can make the difference between a person remaining in their own home or going into a nursing home. Often, medical and nursing-type aids are not the crucial issue and the interfaith visitors can do much to strengthen these individuals. Religious congregations tap into 70% of our population and we can not overlook this tremendous resource in meeting the long-term health care needs of our frail elderly. The 1984 and 1985 Yale Divinity School conferences and individual experience of members of our Connecticut Interfaith Network on Aging group, sponsored by Connecticut Interfaith Housing and Human Services Corporation has brought together most of these church and synagogue-related organizations in Connecticut, and is a powerful testimony to the potential of this group.

6) More active community education programs, such as the Health Expo sponsored by various state departments of health, can also do a great deal for our communities. Other educational efforts which can help promote health and improve the quality of life of our senior citizens, include the video tape library programs, the various state-run humanities programs which encourage groups of seniors to meet weekly to discuss academic subjects of special interest, expansion of the Elderhostel program which encourages travel for older people, and well planned and organized physical fitness programs, sometimes dictated by the particular interests of a community, such as Middletown's hopes to start a Bocci program. This work requires staff members of imagination, and we think the federal government and the Department on Aging can encourage this. But we will have to put together some successful models, such as the Middletown proposal to have one experienced individual responsible for coordinating senior affairs in transportation, housing, and in community outreach. This approach makes more sense and allows a community to do a more effective long-range planning job.

7) The last item I want to mention is the area of paid and non-paid jobs for experienced retirees. Although this is not the subject of the long-term health care panel, it is closely related in that the state of mind of the retired and older individual is often as important as physical health. The feeling of worth and independence which comes with a part-time job or the

satisfaction of mentoring the children of needy single-parent families in a volunteer program, can not be measured. We all want to continue to be involved and it behooves every community and every state department on aging, to put together such an educational program and support it as generously as possible.

Prep by William K. Wasch
7/11/86

SECTION VI: RECOMMENDATIONS

"Middletown is a Terrific Place to Age Gracefully" (see appended Hartford Courant Article of 9/21/84 published after the 9/20/84 Senior Citizens Day.) The survey showed that 98.2% of responding seniors indicated that they intended to remain in Middletown in the years ahead. Throughout the analysis of the survey, the community's support of transportation, subsidized elderly housing, Senior Center programs, CAGM meals, health department, VNA, Red Cross and other social service programs received consistently high marks.

Building on this solid record, Middletown has an opportunity to plan an even brighter future for its older citizens by developing a community-wide planning process using results of the analyses in this study.

These recommendations which have been reviewed by the Senior Survey Advisory Committee are based on the analyses of Senior Center Usage (Section III), Census data (Section IV) and the Senior Citizens Survey (Section V). They apply directly to the goals of the Study and form the basis for the proposed plan of action discussed in Section VII. Highlights of the major findings will be followed by the specific recommendations.

(A) Middletown's 6,250 senior citizens live throughout the city in both downtown and rural sections. The largest number - 1,001 or 16% of the total - live in the Farm Hill section and the second largest of 917 or 14.6% live in the spread out Westfield section. It is interesting to note that 22% of the total Farm Hill population of 4,447 is 60 and older and 7.2% are 75 and older.

Careful study of this data, as well as the survey response that 25.6% of the 60 + households include at least one disabled person, places coordinated transportation service as one of our most important present and future needs.

Recommendation # 1 -

Assemble a Transportation Task Force to investigate future needs and continued coordination of services, and to study other alternatives and options for the community.

(B) An exceptionally large percentage of senior respondents - 73% of those 60+ and 57% of those 75+ - live in homes they own and presumably are maintaining. 13% of the 60+ group and 20.7% of the 75+ group live in subsidized elderly housing complexes. Of additional significance is that 52% of senior homeowners live in households with annual incomes of less than $15,000 and the number of individuals 75+ is estimated to increase by 61% from 1746 to 2813 by the year 2000. This is a classic "house rich - cash poor phenomenon" which must be addressed by the community to meet the needs of this group.

Recommendation # 2 -

Assemble a Housing and Independent Living Task Force to investigate future needs of all citizens 60+ and especially those in the middle incomes. Review the whole range of housing options such as the recently initiated "reverse equity mortgage," accessory apartments, the reeently approved Washington Street congregate housing for the elderly, and other programs to permit older members of the community to remain in their own homes.

(C) Data in the survey confirms that the City is serving its low income elderly satisfactorily with transportation, housing, and a wide range of services and financial supports. For example, according to survey respondents, 46% of the VNA Home Care, 58% of dial-a-ride, and 60% of circuit breaker support is going to elderly households with annual incomes less than $8,000. Also, the most frequent participants in Senior Center activities were individuals with incomes less than $8000, and when related to location the greatest use of services and participation in Senior Center activities was by individuals living downtown.

It is therefore clear that a significant present and future need is to encourage the use of these varied programs by that large number of Middletown senior citizens living outside the downtown area in their own homes on quite modest though not poverty level annual incomes.

Recommendation # 3 -

Assemble a task force consisting of members of the Senior Survey Advisory Committee to recommend to the Senior Affairs Commission a plan to coordinate and intensify community services and outreach throughout the city.

(1) First agree on long and short term goals to enable the Senior Affairs Commission to:

(a) Determine the most effective ways to bring information to Middletown's 60+ population in all parts of the City and at all income levels.

(b) Determine means to establish stable, high level leadership capability for sensitizing the community and developing and implementing broad-based programs for the elderly.

(c) Develop long range capital budget and fund raising program to improve physical shortcomings of the Senior Center and acquire computer capability and other office equipment for efficient management of outreach and programming. Also develop annual operating budget for expanded senior activities and programs.

(2) Specific programs to be considered include:

(a) Chore services for senior homeowners

(b) Education and information programs at Middlesex Community College, public schools, local business, churches and other locations throughout the city.

(c) Coordinated fitness programs with the YMCA, Park and Recreation and Health Departments, and Adult Education program.

(d) Use of films, VCR videos, and other media to educate seniors and individuals with aging parents about the whole range of elderly programs and issues.

(e) A local volunteer coordinating effort to utilize effectively the abilities of experienced retirees in all areas of community service for the full range of age groups and organizations.

(f) A regular Newsletter, radio and local Cable Access programs to bring all types of needed information to senior citizens in this community including-

(g) All discount opportunities for Senior Citizens.

(h) Membership in the Senior Center for all Seniors and close coordination with local AARP and other elderly Groups.

SECTION VII: ACTION PLAN

(A) Publicize widely senior survey recommendations to newspapers and community groups including various neighborhood groups in Middletown.

(B) Distribute Senior Survey Report to:

Selected Commissions, Departments, Health Care Agencies, Service Organizations, Senior Organizations, Advocacy Organizations, and local and regional political representatives.

(C) Present report to Senior Affairs Commission in June 1985 with the recommendation that:

(1) TASK FORCES ON HOUSING, TRANSPORTATION, AND SERVICES/EDUCATION be established, have public sessions at Senior Citizens Day on Friday October 11,1985, and be prepared to report their specific recommendations at the November 1985 Senior Affairs Commission meeting to allow adequate budget development and focus dialogue.

(2) Above TASK FORCES meet publicly and have coordinated public sessions during Senior Citizens month (May) at a major organized gathering at the Senior Center sponsored by The Senior Affairs Commission.

(3) There be a major review of Survey recommendations and followup activities annually at The October meeting of The Senior Affairs Commission.

HOME
Outreach Ministry to the Elderly

The Rev. John W. [illegible]
President Board of Trustees
William K. Wasch
Executive Director

Background on William K. Wasch

William K. Wasch of Middletown, Connecticut is the Executive Director of the Home Outreach Ministry to the Elderly in Middletown. It is a non-profit organization designed to bring a range of volunteer and paid group of social services to isolated elderly in the greater Middletown community to permit these individuals to remain in their own homes. Wasch is also chairman of the Episcopal Committee on Ministry with the Aging for the Diocese of Connecticut and serves as the chairman of the Connecticut Interfaith Caregivers Network which has sponsored two conferences at the Yale Divinity School to help groups throughout Connecticut to start interfaith caregiver programs in their own communities.

WKW/af

381 Main Street Middletown, Connecticut 06457 (203) 347-5661

Statement of Betsy Perkis, B.S.W.

For the past 2½ years I have been the sole family caregiver to my terminally ill mother. My father died 7 years ago, I have no brothers or sisters. I have a small and uninvolved extended family.

My mother has advanced Metastatic breast cancer with a past history of Atril Fibillation, pulmonary emboli, acute corneal rejection syndrone and chronic cellulitis to her right arm secondary to the disease process. She has a large draining chest wound which requires two dressing changes per day. She has cancerous nodules on her right shoulder and arm. Her remaining breast is being affected by invasive nodules. Her right arm is chronically edematous, she has frozen shoulder and has minimal use of her right hand. Her left arm is weak due to an old fracture. She used to have a Hickman catheter in her chest that needed to be Heparinized and dressed daily. She has a rare eye disorder. Her left cornea is being rejected by her own body. She requires eye drops in that eye 4 times daily. My mother has undergone radiation and chemotherapy which helped to slow down the progression of the disease for a period of time. Up until a month ago, my mother could ambulate in the house. Metastatic disease in her femur caused a pathological fracture. My mother required surgery to help alleviate irretractable pain. She was placed at Winthrop Health Care Center last week because she is no longer able to walk. Her prognosis is extremely poor. Bone scans reveal that there is extensive metastatic disease in both femurs, rib cage, spine and in other bones in her body. She is a host body for colonized staph, which settled into her wound 6 months ago. She is a DNR (do not recessitate) status by choice. If she cardiorespiratory arrests she will be made comfortable but will not be recessitated.

When I look for words to describe caring for a chronically ill loved one I can say that it is a strange combination of agony and joy to watch someone slowly and painfully deteriorate, knowing that you have no control over the disease process is perhaps the biggest challenge that one can have to one's sanity. As I watched the disease literally eat away at her body I felt totally helpless. My days and nights were spent revolving around cancer. With each trip to the emergency room, (and there were several) I thought that I was facing her death. I used to daydream of what it would be like. Would I find her dead in her sleep? Would she suffer irretractable pain, unable to eat or sleep? I still don't know the answers to these questions. I do know that she cannot come home to die. I must work fulltime and I am not financially, emotionally or intellectually equipped to handle the end stage of her disease. There were joyful moments during our time together. She has expressed her love and pride over my achievements. I have come to respect and admire her optomism and courage. She has been a source of strenght and support for me. Insomuch as her illness drained me, she replenished me with her overtures of love and appreciation. Last winter when I was very ill with toncillitis, she took on the monumental task of daring to walk up the stairs to my bedroom to see for herself that I was alright. I'll never forget her appearance at the top of those stairs with a glass of water in her hand.

Her illness was not without periods of anger. In the early and middle stages of her illness, both of us would periodically loose control of our tempers. Remnants of past adolescent rebellions arose. Living with a parent after being away for many years can rekindle past behaviors. But a parent who is losing control of their ability to function is an angry parent. Angry at themselves for becoming dependant, and angry at their child for reversing roles. At some insidious point, I became the head of the family. I resented the responsibility and resented her cancer. Both of us were hopeless victims of the disease. My daughter, caught in the middle of conflicts and peacetime became a victim as well. She was governed by the varying moods of the household. Her life revolved around cancer as well.

During the past 2½ years the care that I provided for my mother was supervised by the Regional Visiting Nurse Association. The nurses monitored her vital signs and did dressing changes fro 3 times a week to 7 days a week depending on the needs of her changing condition. They were my lifeline and my sanity. The quality and lenght of my mothers' life was extended because of their expertise and accessability. Nurses were available daily, if necessary. They instructed me on wound care and isolation technique. Medicare recently cut down on the number of nursing visits because of the DRG system. Even though her condition deteriorated, she was not meeting the new Medicare criteria to give services on a daily basis. The cost of her surgical supplies, formerly paid for by Medicare were now partially my financial responsibility.

I was unable to afford home health aides and it was important that I be away from home 9 hours a day. This put my mother at risk. I called her 3 or 4 times daily. Often, I had to leave work to assist her. I was responsible for more dressing changes and I had less supervision.

When my mother was going for radiation and chemotherapy on an outpatient basis, I contacted the American Cancer Society for assistance with transportation. The Society advertises that they provide transportation services for cancer patients to their out patient doctors appointments. I was told by the Cancer Society that drivers are on a volunteer basis, and that they could not obtain a driver to fit my mother's scheduled appointments and also, that there is no guarantee that a driver would be available. Cancellations among the volunteers are high. I had to take time from work to transport my mother. I lost hundreds of dollars in pay during the past 2½ years.

Living with and caring for a chronically ill loved one affects every aspect of life. Even when there is assistance from community resources, the financial and emotional impact of the illness has longlasting and serious implications. There is never enough money, never enough services, never enough respite time to compensate.

I am employed as a social worker at Winthrop Health Care Center in New Haven. My department head and I share a caseload of 120 patients a piece. Winthrop Health Care Facility is a 240 bed pulmonary rehabilitation, skilled nursing and intermediate care facility. It is one of only two facilities in the country that are sanctioned by the State to provide 24 hr. long term and rehabilitation services to patients who are dependent on oxygen, and/or ventilators.

One of my primary roles is that of discharge planner. When a patient is ready for discharge they almost always need community resource assistance in order to manage at home. Often, these discharges involve elderly patients who live alone. The expectations of both families and patients regarding services in the home are often unrealistic. Medicare and Medicaid do not provide reimbursement for 24 hour care. There is no medical insurance that provides this type of coverage. Anything beyond 4 hours per day at the maximum must be paid for by the patient and/or their family. And nursing, homemaker and home health aide coverage often gets discontinued after a few weeks due to the impact of the DRG system.

Medicare does not have a policy for ventilator patients, therefore, patients with medicare requiring ventilators must pay privately for medical care. The Medicare and Medicaid regulations for care of patients in long term care facilities conflict rather than compliment. The reimbursement system is inadequate, therefore, the quality physicians often will not follow a patient in the nursing home setting.

All of these issues place discharge planners and community resources under serious restrictions. The reimbursement system puts patients and families under financial and emotional stress. It severely limits our ability to do effective and adequate discharge planning.

It would be ideal if more community resources could provide pre-discharge patient evaluation. This way, the patient, family and community resource will have a care plan prior to discharge. The problem is that there is not enough money to pay for this service. There is also no funding for discharge planners and community resources to meet and be up to date on each others' services. This leads to miscommunication and misinterpretation. Professionals must be able to have the time and the funding to meet and share information in order to prevent gaps in services and to help improve the quality of health care in the community.

(There is a health care crisis in this country which victimizes patients families and health care professionals).

I truly believe that if our government cannot provide socialized medicine to all individuals, it should provide blanket coverage to all totally disabled people and individuals over the age of 65.

They earned it and they deserve it!

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: The government is cutting back on funds + services however hospitals are discharging people earlier + sicker + they need ~~the~~ more help at home. Also, we need to expand help for chronic care at home. There are thousands of people who are not eligible for T19 but do not have enough funds to maintain themselves, or another at home. We as a country pride ourselves on our lengthy life span but we have done little to put quality into those years! The problems of the elderly are truly a crisis situation given the population explosion of ~~the~~ this group of people and the problem will not be solved quickly.

NAME AND ADDRESS G. [illegible]
[illegible] St. #5
[illegible], Ct 06705

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: As a social worker in a short term rehabilitation facility (Jefferson House) it is my job to help patients & their families find appropriate home care services when the patient is discharged home. There are many excellent agencies that I can draw from but, as was brought out this morning, funding is the critical problem. Medicare covers so little in the way of services & Medicaid is also very limited. The cost for services is very high & most elderly people cannot afford them. It is a sad commentary that Medicaid will cover the cost for long term care indefinitely (in a facility) when the elderly client runs out of funds but will not provide sufficient funding for a client to stay in his/her own home. The federal & state governments could save millions by funding ways to prolong the client's stay at home.

NAME AND ADDRESS
Paula J. Mills
Jefferson House
1 John Stewart Dr
Newington Ct. 06111

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: As we meet here today to talk about the types of care needed to meet the needs of our senior citizens in the area of long term care. Let us not over-look the importance of public awareness and education. We as health care providers and concerned services, should not loose sight of the importance of education and awareness for and about all the areas we are addressing today for the average citizen.

Seniors need to know more, community service agencies, professionals and the public must

be helped to be more informed about each other, as well as our needy elderly.

How can we, as a concerned group, as a state, as a nation help our needy elderly become better consumers for themselves and help those who care for them to do so also

NAME AND ADDRESS M. Colette Austen
[illegible], Public Information
[illegible] House
1 John H. Stewart Dr, Newington, Ct 06111

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: When services are provided with state + federal funds + case management is at the regional level, local services can be overlooked - + duplication can result. This is a key point which was not emphasized today. The local community is one of the partners in long term care, not just the "order taker". The local community has many resources.

You are to be commended for the focus on long term care.

NAME AND ADDRESS Fran Reynolds
Senior Services Coordinator
Westport, CT 06880

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: I speak as a [illegible] physician, [illegible] [illegible] [illegible] practice in the elderly, [illegible] [illegible] [illegible] attention. [illegible] [illegible] [illegible] meetings I am known as the [illegible] old doctor. The health needs of the many [illegible], are not being met because of limited financial resources of those needing attention.

Periodic review of medical management is necessary

Keeping the elderly in their own homes, rather than a [illegible] [illegible] to a Nursing home is much more desirable and reduces mental deterioration.

Too much deductible and [illegible] of 20% insurance to pick up balance is [illegible].

Patients reluctantly call a physician to conserve their financial resources. Recent [illegible] cuts are [illegible] [illegible] [illegible] medicare for the elderly is not appreciated by the [illegible]

The [illegible] problem is a [illegible] one for an increasing [illegible] in elderly population.

Let's give the elderly the [illegible] [illegible] [illegible] [illegible] which they deserve and are entitled.

NAME AND ADDRESS [illegible]
[illegible]
Hamden, Ct. 06514

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: The need of support systems for the elderly in all phases of health conditions, should be developed. This would help to prevent the physical breakdown of the individual. The sooner help in given the longer the individual will stay healthy.

NAME AND ADDRESS Chester Waselouck
66 Monroe St
New Haven, Ct 06513

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: I submitted written testimony — if I had the opportunity to speak I would have read my testimony of personal experience and made statements as a professional working in the health care setting

Thank you for giving me the opportunity to be a part of this experience

NAME AND ADDRESS Betsy Pereis, BSW
240 Winthrop Ave - Winthrop Health Care Center
New Haven Conn. 06511

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: As a medical social worker in a long term care facility it is becoming [illegible] that of all planning one of the major complications of efficient & appropriate confirmation of a d/c date is the lack of transportation services are. It is a tremendous burden on families/friends to appropriately provide for transportation post/discharge to various necessary clinic appointments, errands etc. The DRG system is also causing difficulty for adequate pre-admission screening in long term care facilities: It causes unnecessary readmissions to & from the hospital & Extended Care facilities. This is unfairly shuffling the patient who have no input into the decision process.

NAME AND ADDRESS Barbara [illegible] MSW
Director of Dept. of Social Work
Winthrop Health Care Center
240 Winthrop Ave.
New Haven, Ct. 06511

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: [illegible] service within the [illegible]
[illegible] the elderly [illegible]
[illegible]
[illegible] would be able
meet the elderly need no matter what hat
[illegible] Home Health Aide - Home Maker
Live-in Person etc.
Federal Regulations demand paper statement.
[illegible] — No one gives a damn about
[illegible]
[illegible] need for someone to help in the home the
only [illegible] service would be a person who is willing
to care for the elderly at a reasonable rate of pay [illegible]

NAME AND ADDRESS [illegible] Murphy
[illegible] Lane St.
Ellington Ct 06029

has [illegible]
supplied
with
transp.
[illegible]

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING:

We [illegible] the [illegible] of [illegible] [illegible] provide [illegible] in many instances, [illegible] duplicate [illegible] service—have [illegible] because we appreciated funds to fill existing gaps. I feel there is too much competition [illegible] and [illegible] throughout the state [illegible] service providers [illegible] area.

[illegible] that [illegible] in [illegible] the [illegible] [illegible] For instance, older people are discharged before they are completely recovered from the condition that forced their admission. Since Medi[illegible] [illegible] for [illegible] up to [illegible] months once the [illegible] home, many older people continue to [illegible] of [illegible] care, which the [illegible] cannot adequately fill. I feel [illegible] especially with the population of [illegible] growing, that this system be radically changed.

NAME AND ADDRESS

[illegible]
[illegible] Service Consultant
PO Box 942 Stratford, CT
06497

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: [illegible] health program [illegible] a need to [illegible] of services. This service is presently funded by Dept on Aging at Bella Vista by The Fair Haven Community Health Clinic.

NAME AND ADDRESS [illegible] Coordinator
Fair Haven Community Health
Clinic- 334 Eastern St. 3rd Fl.
New Haven Conn 06513

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: I am 84 years old - am alone - and would like specific information as to who to contact if it becomes necessary for me to do so. I am still able to manage for myself but the future looks bleak. I ~~had~~ have had a heart attack - have athritis - high blood pressure - and other minor ailments.

Please supply me with a telephone number, maybe Mrs. Kelly's office.

NAME AND ADDRESS Mrs. Marie Vincent
310 Eastern St. Apt. D415
New Haven, Ct. 06513
Tel. 469-7393

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: As a supplier [illegible] equipment ([illegible]) [illegible] elderly. We are faced [illegible] informing patients and their caretakers that certain equipment and services will not be covered in the home. These patients and caretakers many times have no where else to turn and many times leave unsafe conditions at home without this equipment. I think that efforts to educate the elderly population about this part of home care have been limited and in the future, there should be resources and programs available [illegible] patient and caretakers [illegible] awareness of the [illegible] regarding these services and home equipment needs at home.

NAME AND ADDRESS Valerie Curbow, R.N.
National Medical Homecare
295 Treadwell St
Hamden CT 06514

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: I feel that it is absolutely imperative that the federal Government act to encourage Insurance companies to provide "Long Term Care" Coverage. From my personal experience working with the elderly on a daily basis, I know that most elderly would prefer paying the premium to being rendered destitute by the cost of L.T.C. especially in the case of those needing care in a nursing home.

NAME AND ADDRESS
[illegible] R.N.
Discharge Planning Coordinator
W.W. Backus Hospital
Norwich, CT 06360

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING:

Prescription drugs are an effective means of controlling diseases and are cost effective. Their proper use can reduce hospitalization and other health care costs. Pharmacists have the necessary knowledge to assist seniors in compliance and avoiding drug interactions and misuse of prescription and non-prescription drugs. More emphasis should be placed on utilizing pharmacists for their expertise in home care programs. HCFA is now attempting to reduce the use of pharmacists in nursing homes to provide drug regimen review. This is short sighted and should be opposed.

NAME AND ADDRESS DANIEL C. LEONE P D
CT PHARM ASSOC
943 SILAS DEANE Hwy
WETHERSFIELD CT 06109

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: A person's ability to get to needed services can be the deciding factor as to whether or not that person can stay in his/her home. To that end, more attention is needed to plan and fund a comprehensive transportation system. Also, many people are forming businesses in providing svcs to elderly on the community level. As a service provider, I believe that these svcs should be monitored to see if these services are of good quality. Furthermore, local municipal agents should be informed of these new services in a timely manner so we might in turn give appropriate information to our clients. Finally we need to explore more types of housing options for older people

NAME AND ADDRESS Carol D. Nerdow, Exec. Director
Orange Human Services
High Plains Community Center
Orange, CT 06477

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING:

I have worked for the past 10 yrs in home care: 2 yrs as a visiting nurse & 8 yrs as a case-manager coordinating home care services for the elderly. I endorse what has been said today. Particularly long-term home care with the cost-sharing on the part of the client. This will provide a realistic plan without completely using federal & private insurance dollars.

NAME AND ADDRESS
Maureen McRelli
77 Cambridge St.
West Hartford, CT 06110

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING: [illegible] need to encourage the development of congregate [illegible]

[illegible] [illegible] of the elderly

[illegible]

[illegible] residents [illegible]

need the support process

Life care facilities must be viewed as insurance

Development of non-profit nursing homes should be encouraged quality of care is more reliable in these than in proprietary facilities

Home care can be cheaper than nursing home care even if it is used by [illegible] [illegible] [illegible] care [illegible] [illegible] [illegible] [illegible] [illegible] cost

NAME AND ADDRESS Regina Deutsch
Health [illegible] Agency of Central CT
131 Beasley Rd
Woodbridge, CT 06525

If there had been time for me to testify at this morning's hearing, "Meeting the Health Needs of our Senior Citizens," I would have said the following:

I object to the one day outpatient operations on the elderly. It often is a great shock to their Nervous systems to go from a crowded hospital to being alone in their apartments where most cannot get decient care. There should be a special ward where Senior Citizens can stay for at least overnight under hospital observation and get the care they cannot get at home.

Name: Irene Moore
Address: 19 Commodore St.
Norwich, Ct. 06360

If there had been time for me to testify at this morning's hearing, "Meeting the Health Needs of our Senior Citizens," I would have said the following:

Question # 1:

What can be done about the very obvious fact that despite the high cost to Medicare, the Medicare Plan is not really meeting the needs of the elderly? The conclusive facts are that senior citizens are now paying as much "out-of-pocket" health care costs percentage-wise as before Medicare was instituted.

The exact solutions are hard to come by, but it would seem some paths are necessary to pursue this [illegible]: 1) [illegible] hospital costs-- which is already being tried with the Prospective Payment System, but which has shown many flaws that need [illegible] and monitoring before proving it as a solution; 2) More Gov't. and State appropriations towards financing Medicare(which would seem hardly likely in view of the recent budget cuts; 3) [illegible] physicians to accept assignment for the Medicare "approved amt." payment. Of course, the AMA would fight this, but an [illegible] effort should be made to [illegible] loyalty to their [illegible]. [illegible] is [illegible] profession has [illegible] to this need. Conn. is now circulating a petition to ask its physicians to follow suit. But it would save time, money, and senior citizens' fears, if this could be legislated on a national basis.

Question # 2:

Why is it, we, the richest country in the world, do not have a solution or insurance plan for catastrophic illness? There have been [illegible] like a hot potato [illegible] for new ones [illegible] would solve the [illegible] of the elderly of [illegible] of being pauperized by long-term illness, or worse yet, being alone and uncared for.

Question # 3:

[illegible] Home Health [illegible] living" with only a [illegible] approach? At present [illegible] for Home Health Care (visiting nurse and home-health aide) only for a short [illegible] of time after hospitalization [illegible] by a physician.

What happens to the patients who don't necessarily need nursing home care, but who could manage independently if they could receive continuous home health aid? I believe task forces and studies have indicated that Home Health Care would be less costly than institutionalization. It also is obvious that as a result of our mobile society, the elderly are often without family or anyone to help them with daily needs such as chore service, meals, or daily health care. There will always be a segment of the population that will need nursing home care, but why aren't we giving more attention to Home Health Care, thereby cutting the percentage of the elderly requiring a long-term health care facility?

Name: Flora G. Ardito

Address: 315 Eastern Street
Apt. D-602
New Haven, Ct. 06513

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING:

I could not attend the first hour of this hearing so I cannot comment on anything that was discussed then. However, in the second hour there was mention of the fact that there is not sufficient money for doing more than is now being done for health care for senior citizens..

It seems to me that there are programs that are being utilized by senior citizens who are financially able to pay for those services, etc.which they are getting free or below cost. I think it would pay for the government to check on senior citizens to see if they qualify for the programs. If there was less cheating by some seniors the government would have more money to spend on health care programs, housing for low income families, shelters for the homeless, etc.

For instance: Regarding the lunch programs where participants pay only $1.25 for a nutritious hot meal. Should not the people who can afford it pay what the meal actually costs which I understand is about $2.50.

Regarding subsidized housing. There are many people who are being subsidized in their rent payments who could afford to pay the full rent if they declared their actual income, or did not transfer some assets to relatives. Some of these same senior citizens are also getting fuel rebates, rent rebates, government surplus goods, etc.

I appreciate that there is much that is being done for senior citizens and the people who are doing somuch on these programs are to be commended. However, if the senior citizens and others who are rightfully not entitled to subsidies were eliminated from the programs there would be more for low income people who cannot afford to pay for necessary services.

CC: Mrs. Mary Ellen Klinck
Commissioner - Dept. on Aging
175 Main Street, Hartford, Ct. 06106

NAME AND ADDRESS Miss Marie Jakomin
Apt. D 417, 315 Eastern St.
New Haven, Ct. 06513

IF THERE HAD BEEN AN OPPORTUNITY FOR ME TO SPEAK TODAY, I WOULD HAVE SAID THE FOLLOWING:

I would have ~~[illegible]~~ stressed the point of fulfilling the client's needs and wants, which should be the basis of any health care planning. As was said, many times the client's wants are overlooked because it may be more complex than putting the client in a nursing home/convalescent home. I think that the attitude of professionals in this field is swinging toward independence for older adults wherever possible.

NAME AND ADDRESS

For Mary Ellen Klink:

Congrats on working towards a waiver for Medicare towards extended home care.

Question: Will this waiver apply for "Home Care Support System" even before hospitalization rather than only after hospitalization. This would be supportive to the [illegible] prevention of hospitalization

Flora Ardito

- Will the Dept on Aging become involved in monitoring and evaluating the many new profit-making bodies that provide services to elderly in their homes?
- Is the Dept on Aging planning a system whereby local agents on aging will be apprized of any new profit-making services in a given region?
- Is there any thought or planning on the state ~~and~~ national level about giving tax incentives for [illegible] to older people who are able and/or willing to buy a house for the purpose of sharing living expenses and mutual assistance?

What are the chances of resurrecting the IRA's as a viable retirement plan for future generations of elderly?

- What are some of the thoughts/plans on the state and national level to put together a comprehensive transportation plan to serve our older citizens?

Carol Nardini
(Town of) Orange Human Svcs
High Plains Community Svcs.
Orange, CT 06477

Since Medicare provides only a portion of doctors fees, and the elderly are asked to pay for more than Medicare allows and creating an economic burden for them. (Question) Do you feel that Medicare assignment should be legislated on a national level?

(To The Panel)

1) Question to Commissioner Klinck -
How efficient is the State survey going to be if many of our patients in the nursing home setting are confused, disoriented, etc? I am a social worker in an area nursing home and I would like to know what variables will be used to determine who is competent enough to be surveyed.

2.) Question to Commissioner Klinck + Commission of the State Dept. of Income Maintenance -

Is there evidence of discrimination between Medicare + Medicaid pts in a nursing homes? As social workers, we need to know how to interpret the new admissions program going into effect. The burden of this job is on us. We need clarification, clarity and consistency on how to implement what the State want.